



Organ Transplantation

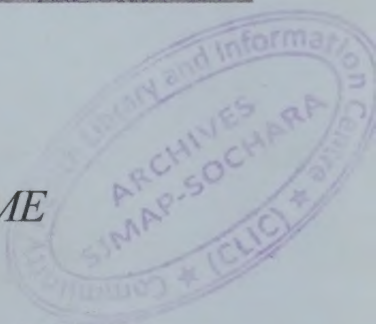
Compassion and commerce



Selected readings from *IJME*

Editors

Sanjay Nagral, Sandhya Srinivasan, Meenakshi D'Cruz



INDIAN JOURNAL OF MEDICAL ETHICS

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Forum for Medical Ethics Society, Mumbai

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Cover image

Picasso's painting of the Minotaur, part human - part bull, from Greek mythology. Many cultures have myths about half-animal, half-human figures. In modern transplantation, xenotransplantation, in which animal organs have been transplanted into humans with poor success, has spawned much ethical debate.

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Introduction

SANJAY NAGRAL

Organ transplantation must surely count amongst the worst ethical quagmires for medical professionals in particular and for society in general – one that, paradoxically, has been created by the tremendous advances of modern medicine. Given its very premise of desperate patients dying of organ failure and a massive demand supply deficit, it provokes sharp, passionate debates and opinions. The subject therefore makes a huge demand on the discipline of bioethics, touching upon morality, religion, politics, gender, economics and philosophy. Indeed, the global ethics conversation has attempted to engage with this subject regularly and in depth.

There is an unfortunate dimension to organ transplantation in the poorer regions of the world, especially South Asia, in the form of an organ market. Unethical transplant practices in the region, as much as they are a failure of regulation and ethical oversight, are also about the fault lines of society, that include class and gender. It is no surprise therefore that the *Indian Journal of Medical Ethics*, which is grounded in activism, has from its very beginning devoted significant attention and space to the subject.

As *IJME* enters its 25th year of publication, we thought of putting together what we believe is a rich and critical contribution to the transplant debate in the form of an anthology. As the reader may appreciate, *IJME* has traversed the spectrum of the transplant ethics discourse over the years, beginning with brief and often personalised comments and moving to more complex analyses. The transformation of *IJME* from a small newsletter to an academically robust journal is also reflected in this anthology.

Transplantation is a subject that pops up in the form of scandal with a sickening regularity every few years in the media in India.

Whilst the media has often performed the role of a whistle blower, its focus is usually on the sensational, and its interest transient. As for academia, with some exceptions both mainstream medical journals and social science publications have largely chosen to ignore the issue. Non-governmental organisations working in the area have generally focussed on public campaigns to promote deceased donation. Thus *IJME* has partially filled the need for a thorough analysis through the moral, social and cultural prisms that this subject deserves.

The articles in this collection are presented in the order that they were published, and are not grouped according to any theme. Given the nature of the subject, it is unavoidable that certain issues have been revisited more than once over the years. The articles were chosen as they flag some of the critical themes and represent viewpoints of some of the key players. The contributors include medical professionals at the forefront of efforts to ensure ethical transplant programmes.

For example, the essays by Mani (1995) and Colabawalla (2001) are commentaries on ethical dilemmas by two senior physicians who were pioneers of transplantation in India. The responsibilities of medical professionals are repeatedly mentioned in the articles here. There are, of course, debates on the ethics of paid transplants and a regulated trade – in the form of arguments supporting it, by Radcliffe Richards (1996) and Kyriazi (2001), with responses by Pilgaokar (1996) and Thomas (2001). More recently the argument was resurrected by Aggarwal (2016), with a response from Martin (2016). A report by Jayakrishnan and Jeeja from Kerala (2003) is illustrative of how the kidney trade works and of the inadequate response by monitoring agencies, the police, and professional associations. In 2007, a joint editorial by Indian and Pakistani authors (Jafarey, Thomas, Ahmad and Srinivasan) focussed on South Asia as the theatre of this phenomenon.

In the last few years, deceased donation has been at the centre of public and media focus in India. Promotion of deceased donation has resulted in an increased rate of deceased donation in some states. However, it has led to its own set of dilemmas, especially the unfortunate manner in which the Indian law has linked brain

death and withdrawal of life support for donation. One of the articles (Pandya 2001) specifically looks at this issue. The role of authorisation committees formed under the Transplantation of Human Organs Act is also examined in a report (Shroff 2007). A comment by a transplant coordinator describes the barriers to strong deceased donation programmes (Deshmukh 2001). Articles have also explored the pros and cons of methods to increase availability of the deceased donor pool, such as presumed consent (Kaushik 2009; Jafarey and Moazam 2009; Nagral 2009) and non-heart beating donation (Bardale 2010; Nagral 2010).

In 2014, *IJME* devoted a theme section to deceased donation. The contribution from India (Nagral and Amalorpavanathan) traces the history of this movement in India whilst also identifying its problems. The experiences of deceased donation programmes in Pakistan (Moazam and Jafarey), Kuwait (Mousawi), Oman (Mohsin et al) and the Philippines (De Castro) form a part of this group. The need for coordinated and sustained efforts by governments of both affluent and low income countries and by medical professionals to eliminate organ trafficking emerged as an important issue in this discussion.

One of the responses to the shortage of cadaveric organs has been the expansion of live donor transplants for organs like the liver. In what is a very formidable operation for the donor, the issue of danger to the donor's life and related informed consent has also been the subject of intense debate. Pieces from *IJME* on this include a pioneer surgeon's perspective (Soin 2003). Elsewhere, the anguished narrative of a son who lost both his parents, one a donor, the other the recipient (Srinivas 2005), is carried alongside the concerned hospital's response (Prasad 2005).

This collection also reflects *IJME*'s unique role in bringing together perspectives from other countries including our South Asian neighbours, especially Pakistan which has contributed extensively to the discussion. These viewpoints are especially relevant to the topic as trafficking and sale have regional and international dimensions. We thus have articles from Iran, which has a unique history of state-supported paid live transplants and a fledgling cadaver-based programme (Einollahi et al 2007),

and a study of gender imbalances in live donation (Nourbala et al 2007); Brazil, which has one of the largest state-supported transplant programmes in South America (Ferreira and Guedez 2011); Singapore, which developed an extensive legal framework, which included presumed consent in 1987 (Chin and Kwok 2014); the Philippines which is trying to curb the organ trade (De Castro 2014) and, more recently, Israel (Epstein 2016).

The last two pieces in the anthology, which have just been published online, take the debate to newer dimensions. Epstein (2016) brings up yet another complex and disturbing phenomenon, called conditional donation, in this particular case what the author chooses to call 'sectarian' donation. This issue came up in Mumbai a few months ago in the form of a conditional deceased donation. As deceased donation expands, such fault lines will inevitably play out across a society as divided as South Asia. Finally, in the last piece by Siby George (George 2017) we have the philosopher's reflective view of body politics in the context of the entire spectacle of transplantation.

I believe that this compendium besides representing valuable resource material is also a reflection of what a bioethics publication can and should do given the increasing technology and commodification in healthcare. Given the recent exposes of kidney rackets as well as the prominent publicity to deceased donation it is also very timely. With the Government of India launching a national organisation (National Organ and Tissue Transplant Organisation) to regulate and oversee transplantation and sharing of organs across states, this is an opportune moment to flag the relevance of the ethics discourse in this field.

This anthology, which is being released on the eve of the 6th National Bioethics Conference, a biennial gathering held under the umbrella of *IJME*, will be the third such volume from the journal. For some of the regular readers and well-wishers of *IJME*, this book may also be a vehicle for looking back on a journey of twenty-five years.

Ethical problems in renal transplantation: a personal view

M K MANI

The golden age of medicine for the individual medical man was the last century. There were few effective drugs available and all the doctor could do was to 'cure sometimes, to relieve often, to comfort always.' No one expected a doctor to prolong life, and the profession had little responsibility and every opportunity to be noble. Medicine was an art and hardly a science.

The last fifty years have been a golden age of a different sort. There has been a logarithmic increase in our knowledge of diseases and in our therapeutic armamentarium. It has not been an unmixed blessing.

***Primum non nocere* (First, do no harm)**

The power to do good always carries with it the capacity to injure. Effective medicines have horrendous side effects and we often do active harm to our patients in our efforts to help them. Many of us face tortuous decisions day after day. Should I put a patient on cyclophosphamide for glomerulonephritis? Will he suffer some serious infection and die as a result? If I withhold the drug, will he die of renal failure which could have been prevented? Should a surgeon take a patient for an operation which carries risk to life? Is he sure the patient will die of the disease and cannot recover with conservative treatment?

All these dilemmas pale into insignificance beside the predicament in which transplantation places us. The worst of all is renal transplantation, because the kidney, being a paired organ of which we need only one for life, can so easily be removed from a living person. This leads us to perpetrate the ultimate in horrors,

a hazardous operation on a healthy person, grievous hurt by the 'healing profession'. A few of us have been catalysts in the development of renal transplantation in this country. I do not know whether to pride myself on this, or to hang my head in shame.

The patient with chronic renal failure: options and costs

Let me begin by stating a few basic facts. The patient with chronic renal failure has three options, each with subdivisions. First, he can receive a renal transplant, which could be from a relation, a live unrelated donor, or a cadaver.

The main difference between these is that he has a good chance of success with a related donor even if he uses azathioprine, which would cost him approximately Rs 5,000/- a year, but the unrelated kidney from a live or cadaver source will be successfully grafted only if he uses cyclosporine for a period, and this drug costs Rs 100,000/- a year. Many doctors claim to have successfully weaned their patients off the drug after some time, usually a year, but that still means an additional cost of Rs 100,000/-.

What must be stressed is that cyclosporine has only made a difference to short-term survival of the graft. Long-term survival depends on the degree of matching between the donor and the recipient. A full-match sibling-graft has a half life of 25 years. Any other half-matched relation has a half life of 12 years. The unmatched cadaver or unrelated live donor graft has a half life of 6.5 years, even if cyclosporine is the immunosuppressive used.

Second, the patient can stay on dialysis. This could be haemodialysis, which he could take in hospital for a cost of Rs 120,000/- a year, or at home for a cost of Rs 250,000/- to buy a machine, and then Rs 50,000/- a year for its running. He could go on Continuous Ambulatory Peritoneal Dialysis for a cost of Rs 130,000/- a year and could carry out this treatment at home.

Both these modalities are now available in some centres in India, and the long term survival is good, with a reasonable quality of life.

Third, the patient could quietly go home and die. From the point of view of the family, this is often the best option. Whatever the

treatment, it is expensive, and usually the family is poorer for it. Treatment often requires the sale of property or the need to take large loans, and only a few people in our country earn enough to repay them and leave the family richer than it was before the illness struck them.

The only option at least a few Indians can manage on their own income is a related donor transplant with azathioprine. I have seen gold chains disappearing from the necks of ladies and being replaced by a yellow cord to hold the mangalsutra, and silks yielding to faded cottons and I have been left with the guilty feeling of having pushed a family into poverty. Ethical dilemma No. 1.

The kidney donor

Let us now turn our attention to the donor. We always reassure him or her that the donation of an organ is quite safe and that life can be carried on safely with one kidney. True, but the kidney is removed by a major operation and all major surgery carries a definite though small risk to life, perhaps 1 in 1,000.

The newspapers carried reports of two donor deaths in Madras during the last few years and there might have been others which did not attain public knowledge. Hospitals and transplanting doctors do not publicise their failures, especially donor deaths. If the donor of a kidney gets a renal disease himself later in life, he has a smaller renal reserve and will go into renal failure much faster, than if he had both kidneys available. It is mandatory that we should stress the risks when we talk to the prospective donor, and that our conversation should be confidential and that he should be given the option of telling the doctor that he does not wish to donate the organ. The doctor should then invent a medical reason for not accepting the donation, so that the family should not be aware of the reluctance of the donor designate. This is ethical dilemma No. 2.

I have always regarded a medical certificate as a sacred document and think poorly of doctors who attest to falsehoods, and yet I have to tell a lie to preserve harmony in the family. I have done this on at least three occasions. Once, the prospective donor told me,

three days before the operation, that she had changed her mind. I hurriedly ordered a test and in collusion with the biochemist, had it reported marginally abnormal and therefore declared the donor medically unfit. I had to listen to a well justified diatribe from the husband of the patient for my carelessness in not having done this essential test earlier and for having put the family to great inconvenience and costly delay.

The unrelated live donor: adequate compensation for risk?

The greatest problem lies with the unrelated live donor. The idea of someone having to sell a part of his body for any purpose is repugnant to us and our reflex reaction is to abhor it. Let us think it over rationally.

There are three parties involved. The donor who sells his kidney, the patient with renal failure who buys it and the medical man who serves as a broker, a commission agent who effects the transfer of ownership. In view of the multitude of active programmes all over the country, it is clear that all three parties are happy about the present situation and are willing and even keen on perpetuating the present practice. What right has anyone else to intervene? The patient is a man or woman on the verge of death, clinging desperately to a hope that this operation will bring him or her back to a full life and not necessarily one treacherously exploiting the working classes. The donor is a poor man with the laudable objective of earning some money by the sale of his only asset, perhaps to educate his son, perhaps to get his daughter or his sister married, perhaps to pay for an operation on his wife. He or she is not necessarily a drug addict seeking the wherewithal for the next fix. The doctor is a noble soul, desperately trying to save his patients at great difficulty to himself and not necessarily one who is interested only in the money he can extract from the recipient and in retaining for himself the lion's share of the proceeds. Unless otherwise proved, we have no right to view any of the three as anything other than what they claim to be.

But nagging doubts continue to assail me. Let us begin with the patient. Has he or she been informed that the half life of the

kidney will be only 6.5 years, in other words, that he or she has only a 50% chance of the kidney lasting more than six years? Has the doctor mentioned the fact that there is no certain way of establishing whether the donor has some viral disease which could cost the life of the recipient, that the tests now available are not 100% reliable, and that the person intent on selling an organ is not going to release information which would preclude the sale of the organ? Has the patient been told that there are excellent alternatives with less of such risks, the different forms of long term dialysis?

The biggest source of doubt, of course, is the donor. Would he be as willing to give his kidney if he knew that donors can die as a direct result of the operation? The chances of dying are small, but not negligible. What about the risk of his developing renal failure himself, due to some renal disease developing later? I have seen renal failure years after nephrectomy in three of my donors. Two went into the end stage and needed renal replacement. My donors are all related and the family rallied round and someone else offered each of them a kidney. What is the chance of this happening with an unrelated donor?

We are, of course, exploiting poverty all the time. I do not climb the coconut palms in my garden, but pay someone else to pick the nuts which I enjoy. We pay people to entertain us at the risk of their lives, trapeze artistes and lion tamers, for instance. There is a difference. They are living by their skills; the renal donor is at the mercy of the surgeon. Is he being paid a realistic sum for his sacrifice? Who decides that Rs 5,000/- or Rs 10,000/-, or even Rs 50,000/- is adequate compensation for an irreplaceable asset, for life itself? This is a buyers' market, where the buyers are all rich and the sellers are all making distress sales.

Noble medical profession?

The greatest mistake mankind ever made was in describing the medical profession as noble. We now claim nobility in all our actions, and doctors doing unrelated donor transplants say they have to do it because they are committed to their patients and have to do it to save their lives, however distasteful the means.

The argument is specious. We do transplants only for some fraction of the people with renal failure in the country, maybe two or three percent. Have we no duty to the rest, who are too poor to come to us in the first place? Have we no duty to the donor? We ease our conscience by saying that the donor is well rewarded by being given the wherewithal to pay his debts or to buy a hut or a bicycle. If we were really interested in the donor, would we not organise an international auction for his kidney? Surely the rich Arabs and Chinese who buy our kidneys could pay lakhs for them instead of this pittance. Should not the donor receive more for the transplant than the medical man who is merely a broker in the deal? If a broker helps me to buy or sell a car, he receives only a fraction of the price, not the lion's share.

Kidneys from cadavers

We are told that the country is not ready for cadaver transplantation because it is costly and requires a complicated technological set-up. This is nonsense, an argument raised by vested interests. The set-up in the West today is elaborate and well beyond our means, but so is every aspect of medicine. Even a live related donor transplant in the West is done with a degree of sophistication beyond us, at a cost at least 20 times as much as here. I was involved in a cadaver transplant programme in Australia when transplantation was in its infancy all over the world. The concept of brain death did not exist. We waited for a person to die in the old fashioned way, by entire and continuous cessation of respiration and circulation and then took the kidneys within an hour of death and got a reasonable 60% one year graft survival, using only azathioprine. There are units all over the world which are using such donors today, people who die outside hospitals or before they get on respirators and their results are only marginally worse than those with heart-beating donors. In 1968, Australia did not have sophisticated computers and transnational movement of organs. All kidneys harvested were used within the city, within eight hours and I see no difficulty in establishing the same system in Madras. The cost would be rather less than that of the unrelated live donor, as we can do without a number of investigations needed to safeguard the life of the donor. We need to have the backing of the public

for this, with wholehearted willingness to donate organs after death. The effort that the unrelated donor lobby is using to prevent cadaver legislation would better be utilised to persuade the public to accept the concept of donating all organs after death.

We have an Act to regulate transplantation now. It is a far sighted piece of legislation, bringing in the concept of brain death, making it possible for us to decide during life that we wish to donate organs after death, firmly prohibiting commerce in transplantation and introducing some regulation of the whole transplant industry. Of course it has flaws and many people on both sides of the question have spent much time pointing out where the law would be misused. It is up to us to put it to good use; and the effort we have spent arguing about it would have been better utilised had we got on with the job of making it work.

The gift of life

Unrelated live donor transplantation should be banned because there is an alternative for the patient with terminal renal failure in the form of dialysis or cadaver transplantation, because the donor will always be a poor and ignorant man who will be exploited by the doctor, the patient and the broker and because we will never have cadaver transplantation unless the easy way of buying a kidney is closed to the rich and influential. They will then turn their efforts to establishing cadaver donation in the country. A time will come when it will seem quite natural for every one of us to give life, even as we leave the world, with gifts of kidneys, livers, hearts, lungs and to give sight to the blind. Our organs will live on after us.

This is truly the path to immortality.

Originally published in *Medical Ethics*, July-September, 1995

Organs for sale

JANET RADCLIFFE-RICHARDS

Introduction

When evidence of trade in organs for transplantation from live vendors reached attention in the West, widely different groups indignantly denounced it. Restricting my remarks to kidneys, I suggest that this indignation is misplaced.

Those criticising the rich for greed appear to lose sight of the fact that those seeking kidneys are dying individuals trying to save their lives. Each of us will do everything we can to save our lives. If anything, spending money to save one's life involves less greed than does spending money on luxuries.

The critics' attitude towards the poor selling organs is even odder. The young Turkish father swept on to everyone's television screen wanted to sell his kidney to pay for urgent hospital treatment for his daughter. By banning this sale, we deprive him of his best option and leave him with one he considers even worse than the loss of a kidney. Our indignation on behalf of the exploited poor seems to take the curious form of making them even worse off, leaving behind a trail of people dying who might have been saved and another of people desperate enough to offer their organs who are thrust back into the wretchedness they were hoping to alleviate. To respond that no one should be in these desperate situations is idle and wishful thinking.

Let us consider the arguments against the sale of organs one by one.

Autonomy and consent

Many claim that there can be no genuine and free consent to the sale of organs. It is argued that would-be organ vendors are poor,

undereducated and underprivileged and do not comprehend the risks. If this argument be expected, such individuals should not be accepted to comprehend the risk of donating an organ either. In either case, the solution lies not in banning the procedure but in counselling and dispelling ignorance. Where there is genuine incompetence to consent, someone competent must make a decision on their behalf as is the prerequisite for any procedure with potentially serious consequences such as abortion, AIDS testing or surgery.

Others argue that would-be vendors are coerced by poverty and since coerced consent is not real, the choice should not be allowed. Coercion is something that reduces the range of options open to an individual, so there is a sense in which poverty can be said to coerce people into selling their organs. The only way to remove this coercion, however, is to widen their range of options, preferably by removing their poverty. Banning the sale of the kidney only reduces the options still further. To the coercion of poverty is added the coercion of the supposed protector who comes and takes away the best that poverty has left. This cannot be justified by concern for freedom and autonomy.

Even if this argument did work, it would still make no distinction between sale and donation of an organ. In the latter instance, the coercion is the threat of impending death of a relative, quite a potent form of coercion, you will agree. The logic is the same.

It is also claimed that vendors are coerced when they are made unrefusable offers of several times their annual income. Such an offer, however, does not narrow the options open to the individual. It broadens the range. The original options are still there. If you ban such offers, you are constricting options, not removing a coercion.

Harm to the vendor

It is also said that State paternalism grounded in social beneficence dictates that the abject poor should be protected from selling parts of their bodies. Advocates of this idea do not explain why the poor are misguided in their judgement that organ selling is in their best interests. The assessment of the potential harm of

losing a kidney as weighed against the potential benefit of whatever payment is received is, at best, not easy. The risks of hang gliding, rock climbing or diving from North Sea oil rigs are much greater than those of nephrectomy. It is plausible to say that the expected benefits will be much greater to the desperately poor who see in selling a kidney the only hope of making anything of their wretched lives, and perhaps even of surviving, than to the relatively rich. If the rich who take risks for pleasure or thrill of danger are not misguided, why are the poor who take far lower risks for much higher returns considered irrational and in need of saving from themselves? And again, if we could reach the general conclusion that selling a kidney is bad, the argument applies equally to donating one. If any aspect of organ selling is against the interests of the vendor, it is not the gaining of money but the loss of a kidney, and this loss is identical for donor and vendor. There is no reason to presume that whatever the money is wanted for must matter less to the vendor than saving the life of a relative must to a donor. The exchange of money is not even an indicator, let alone a determinant, of the difference between reasonable and unreasonable risk.

Harm to the recipient

Here the question is not of whether the purchasers are less well served than they ought to be but of whether they would be better off without the trade. Clearly most would not. Even if treatment carries a significant risk of disease, the alternative for most of these patients is certain death.

Furthermore, even if the risk were not worth taking in the present circumstances, that would be an objection only to the inadequacy of control rather than to the trade as such.

Collateral damage

The trade is alleged to be wrong because it treats parts of the body as purchasable commodities. We should, however, guard against the common trick in rhetoric of using a term carrying derogatory overtones without proving the grounds for such condemnation. A fundamental issue of autonomy is involved here. Treating

people as commodities — with no say in their destinies — is vastly different from letting them decide for themselves what to do with their own bodies. Whilst it may be degrading to be in a state where organ selling is the best option left, this does not mean that actually selling the organ worsens the degradation. On the contrary, many vendors may feel an increase in self-respect after what is perceived as a duty done.

The argument that such trade will invite social and economic corruption is difficult to support as all available evidence only goes to show that these, in fact, follow prohibition.

It is said that if organs are bought from living vendors there will be no incentive to overcome resistance to transplantation using organs from cadavers, because people in positions of power will be able to buy kidneys and will have no incentive to press for the cadaver programme. But it might be equally claimed that since these very people are the ones who will respond with disgust to the trade, its continuation might induce them to press even harder for change.

Exploitation

An objection of a different kind is that the trade must be stopped because it involves exploitation. The poor are vulnerable to exploitation and they should be protected. Stopping the trade, however, is still taking away the best option of the poor, which makes it rather like trying to end the miseries of slum dwelling by bulldozing slums or stopping the problems of ingrowing toenails by chopping off feet. We put an end to that particular evil, but only at the cost of making things even worse for the sufferers.

If our aim is the protection of the poor and we lack the will or the power to remove the poverty that makes them exploitable in the first place, the next best thing is to subject the trade to stringent controls.

Conclusion

I find trade in organs as intuitively repugnant as does everyone else but strong feelings of a moral kind, by themselves, cannot form reliable guides for action. Remember the traditional reactions to

inter-racial marriage, unfeminine women and homosexuality themselves now widely regarded as repugnant? If we find the trade repugnant because of the harm it does to vendors, we must find the idea of making their situation worse by stopping the trade more repugnant. The worse we think it is to sell a kidney, the more repugnant should we find any objectively worse alternative. We should find it much more repugnant that the Turkish father should be forced to keep his kidney and watch his daughter die than that he should sell it and save her. We should also find our repugnance proportionately lessened if we could assure high standards of care that would make the harm minimal.

This does not prove conclusively that organ sales should be allowed; good arguments for prohibition may still be found. The fact that so many bad arguments are used, however, shows that good ones must be hard to come by, and it also suggests that our strong feelings of repugnance are systematically distorting our arguments. We are in effect treating the removal of our own feelings of disgust as more important than the real interests of the people on whose behalf we claim to be concerned. It is therefore morally essential to understand the power of these feelings so that we can think impartially about the problem.

In the meantime, until someone produces a far better argument than has yet appeared, there seems to be no escaping the provisional conclusion that the prohibition of the sale of organs does substantial harm of various sorts, that these have not been shown to be justified, and therefore that we should not be trying to prevent the selling of organs but rather to lessen whatever harms are now involved and to increase the benefits to both vendors and purchasers by getting the trade properly regulated.

This essay is an abbreviated version of Dr Radcliffe-Richards' essay 'Nephrological goings on: kidney sales and moral arguments', Journal of Medicine and Philosophy. 1996; 21(4): 375-416. When giving permission for publication in IJME, Dr Radcliffe-Richards asked us to point out that this summary of her arguments was prepared by our editorial board, and she might have placed different emphasis and used a different style. We have not heard back from Dr Radcliffe-Richards on her permission to reprint this

article in the anthology, but felt that it was important to carry this perspective and took it that her permission for its initial publication justified this reprint.

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Organs for sale (continued)

ANIL PILGAONKAR

Dr Radcliffe-Richards deserves applause for making us think.

In her essay entitled *Organs for sale* (1), Dr Radcliffe-Richards puts forward arguments that make you ponder. She points out that the banning of sale of organs might, in fact, restrict the options available to the already poverty-stricken person, in need of funds for dire needs, and that this might be unethical. The examples she has cited are eloquent. At the same time - as can be judged from the uproar against the sale of organs by donors not related to the recipient, and against clandestine 'deals' of organ sale/organ transplants - public opinion overwhelmingly supports the ban of such sales. It would indeed be sad if the issues raised by Dr Radcliffe-Richards do not generate debate. Dr Radcliffe-Richards confines her observations to the scene in the West and to the sale of kidneys. My response to her essay is confined to the scenario in India (which has recently witnessed the most unethical marketing/procuring of organs for sale) and will, I hope, stimulate readers to debate the subject.

Individuals surrender some rights when they form society

Laws regulate society and any regulation that is unjustified ought to be considered unethical. The liberty and autonomy of individuals comprising society are paramount. It is also true, however, that individuals voluntarily give up a measure of their freedom when they agree to form any society. The justification for such limitation on freedom follow upon the additional advantages which, without the formation of society, would not be available to that individual. One example of such a limitation of an individual's freedom that is beneficent to society is that on intrusion on the

freedom of others. Such limitations attempt to balance the good of the individual against that of society.

This is the ultimate goal of ethics. In an ideal society, where such a balance exists, there would be no need for laws. Legal regulations –viewed from this perspective -- must be considered as pragmatic measures, to be jettisoned as soon as they become redundant.

Sellers and buyers: both victims of circumstance

Those selling or donating organs and those purchasing or receiving them are equally victims of circumstance. One is stricken by poverty and the other by disease. For us to accuse or blame one victim or the other is unfair, unjustified and in poor taste. None would contest this point made by Dr Radcliffe-Richards.

Deserving of condemnation - the middle men and the regulatory agencies

What is repugnant is the attitude of the middle men –the doctors and the agents –who, to say the least, have exploited the vulnerability of these victims. Almost every purchaser of an organ has been rich. Those coming to India from the Arab countries have found it difficult to seek legal remedies for the wrongs done to them. Cases of mismatched organ transplants, made to function only temporarily –through the use of powerful immuno-suppressant drugs–have left the recipients in a chaotic state. Some have been infected by HIV. A significant number of those selling organs have been cheated either by being conned into ‘informed consent’ or by being paid a paltry fraction of what the middle men received. Reports of ‘donors’ entering hospital for surgery unrelated to the kidney and returning minus a kidney are on record. It is difficult to imagine that the involved doctors were ignorant of these practices. More likely, they found it profitable to look the other way—even when the exploitation was obvious.

The silence and inaction of regulatory bodies like the Medical Council of India and the state medical councils can only be severely condemned. They have preferred to turn a blind eye.

Exploitation

The question that arises is: ‘Why penalise the victims and rob them of the little they have?’ The answer lies in the society that we live in. There are many instances of such unfairness and insensitivity.

Prostitutes are forced into the trade because of poverty or insecurity. They are victims. The offenders are the individuals who force/lure them to the trade and those who use them for their pleasure. Even so, society accepts laws to regulate these victims as pragmatic solutions.

Child labour is repugnant but a child who labours and its parents are victims. Banning child labour robs the child and its family of options that help them survive. Yet the law banning child labour has been accepted on the premise that the State will work out means to provide sustenance to the victims.

Bonded labourers and slaves have been the victims of inhuman society. When such practices were banned, the victims were robbed of the resources provided by the often tyrannical landholders. The State justifies the ban by providing doles to the victims – a pragmatic alternative.

All the arguments that Dr Radcliffe-Richards puts forth in respect of (a) autonomy and consent; (b) harm to the vendor; (c) harm to the recipient; (d) collateral damage; and (e) exploitation are applicable to these cases also.

Why have such laws? What justification do they have?

I view laws as forming two categories. One group is promulgated to set order or to pre-empt disorder (as in the case of a declared state of emergency or for pre-emptive arrests). The other set enables administration of justice. It is obvious that the former ought to be pressed into existence only when absolutely necessary in the larger interest of society and must be short-lived.

Transplantation of kidneys started as a noble activity to provide viable options to hapless victims. The vulnerability of the patients on the one hand and the poverty, ignorance and helplessness of the potential donors on the other soon suggested avenues to be exploited by middlemen. When the medical councils – established

to regulate the medical profession – preferred to remain silent and inactive, it was left to the press to voice concern, but this was generally disregarded. The medical profession found fertile ground to pursue its trade. When the Consumer Protection Act was judged to be applicable to the medical profession and cases of the sale of organs were heard by the court, a curb was imposed.

It is true that the state took the softest option – to pass a law to ban sale of organs – the argument being that the trade cannot be sustained without money. In the process, as pointed out by Dr Radcliffe-Richards, the options of the victims were reduced. What is more, it is naive to believe that a practice can be discontinued merely by passing a law.

Why, then, do we tolerate such laws?

Society has linked law with order. Whenever there is disorder, people have looked to legislators and enforcers for relief. This is so in the kidney trade. Laws banning sale of organs are attempts at instilling order in the chaotic situation brought about by exploitation of society by the middle men (doctors and agents). One would expect the ban to be temporary. Once it is agreed that these are pragmatic measures, the State, the legal and medical councils, and the medical professionals must also take on the responsibility of ensuring conditions that make these measures redundant.

What are the measures that can be taken towards this end?

Making full use of organs from cadavers. Some voluntary organisations in India are already working in this direction. *Deha Dan* (donation of the body after death) is one such, interacting with the people to ensure a positive response. It will be some time ere the traditional aversion to ‘mutilation of the corpse’ will give way to free voluntary donation of organs. We also need efficiently run organ banks and a system for transfer of organs to where they are urgently needed. Facilities and procedures for the removal of organs and, indeed, postmortem examinations, must be upgraded

and humanised. If the utilisation of cadaver organs is to become a reality, transparency, fair practice and humane attitudes must prevail.

Utilising fully the organs of the brain dead. We must not lose sight of the fact that human beings are both crafty and ingenious. Measures must be in place to ensure that there is no misuse. The use of organs so obtained must be restricted to a few, but well spread out, centres of excellence where 'audit (medical, financial and social), review and report' of the organs re-cycled and the outcome is standard practice. Organs obtained from cadavers and those who are brain dead must be rationed only on the basis of need.

Despite these measures, we shall still need organs from live donors. Such donation must be untainted by commerce. Public scrutiny of all such operations could curb backdoor trade. It is fair to expect that organs are taken from live donors only after the other avenues prove inadequate. This still does not address the situation where poverty leaves a person with no other option but to sell his organs to meet the medical expenses of a critically ill niece. Why should such options be denied to the person when the welfare State cannot alleviate his desperate need?

There are no easy answers. What makes it more difficult for the State is that such individuals are legion. No humane society ought to force its members to sell their organs, especially to ensure healthcare. The State must provide free/subsidised healthcare in every such case. And if this is not forthcoming, the treating doctor would be ethically justified in abetting such a sale after publicly highlighting the cause for sale of the organ. Going against the law in ethically meritorious situations is far from shameful provided such action is transparent and without vested interest.

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The ethics of organ selling: a libertarian perspective

HAROLD KYRIAZI

First principles

As a libertarian, I believe that people own themselves. Any alternative would involve some form of slavery. And as owners of themselves, individuals have the right to sell their organs, give them away, and even to allow themselves to be 'harvested' of their organs in a productive form of suicide, for whatever reason they choose. (Of course, surgeons and hospitals would be free to denounce, and to refuse to perform, such macabre procedures, and medical societies would be free to expel members who assist in such suicides.) Having said that, I also wish to emphasise that I share the concerns expressed by bioethicist Stephen G Post, of the Case Western Reserve University School of Medicine's Center for Biomedical Ethics:

...in India, where a huge black market in nonvital body parts provides kidneys for the wealthy, it is the poor who sell. Is this truly freedom, as the libertarian proclaims? Or is it a forced choice made in destitution and contrary to the seller's true human nature? I see such a market as the most demeaning form of human oppression, as unworthy of any valid human freedom...(1)

But one could make the same argument for coal miners and others with dangerous jobs, who risk life and limb to support their families. Certainly such people are better off having these additional choices. But while it is a pernicious paternalism that would seek to deny the poor these choices, it is also a sterile libertarianism that would stop the inquiry here, hailing the enlarged freedom of the destitute, and looking no further.

Margaret Radin, professor at the University of Stanford Law School, reached a similar conclusion:

If people are so desperate for money that they are trying to sell things we think cannot be separated from them without significant injury to personhood, we do not cure the desperation by banning sales. ... Perhaps the desperation is the social problem we should be looking at, rather than the market ban. Perhaps worse injury to personhood is suffered from the desperation that caused the attempt to sell a kidney or cornea than would be suffered from actually selling it. The would-be sellers apparently think so. Then justice is not served by a ban on “desperate exchanges.” ... We must rethink the larger social context in which this dilemma is embedded. We must think about wealth and power distribution.(2:125)

And so we are led to consider the larger societal question of basic economic justice. But before discussing the world as it should be, I wish to make a few comments about the ethics of the world of organ transplantation as it is.

Comparing the Indian and US situations

Both India (three of the key states in 1994, and others subsequently) and the US (nationally in 1984) have banned monetary compensation for human organs. The ban has been effective in the US, while it is routinely circumvented in India. But which system is the more ethical? In India, at least, those upper class Indians and wealthy foreigners who need organs are getting them, while some of the poor are afforded more financial opportunity than they would otherwise have. In the US, however, over 5,800 people — rich and poor alike — die every year while waiting for donor organs that never arrive. And with most such deaths are associated years of waiting, years of debilitating sickness, and years of mental anguish not only for the ill, but for their families and friends. Against this horrendous backdrop, is a ban on market activity ethically sound? Another professor of law, Lloyd R Cohen, of the George Mason University School of Law, thought not:

People are dying while the organs that could restore them to life, and that a market (3) would provide, are being fed to

worms. Were more to suffer and die for want of organs that a market would provide, the high minded pieties that support the prohibition would be revealed for the vacuous moral posturings that they are.(4)

Finally, on this issue, Professor Radin insightfully notes that the US position — that altruism shall be the only permitted motivation for organ donation — may simply be a convenient way of shutting its eyes to the desperation of its own poor. “To preserve organ donation as an opportunity for altruism is also one way of keeping from our view the desperation of poor people.” (2: 126)

Let us now proceed to the heart of the matter — poverty and economic justice.

Economic justice

The essence of economic injustice, as it is currently instituted — essentially worldwide — is no longer chattel slavery, as it was in the 19th century and before, but wage slavery. And wage slavery is made possible by land policies that allow a small portion of mankind to monopolise the land on which and from which all must live. Said 19th century American economic and social philosopher Henry George,

...the ‘iron law of wages,’...which determines wages to the minimum on which laborers will consent to live and reproduce...is manifestly an inevitable result of making the land from which all must live the exclusive property of some. The lord of the soil is necessarily lord of the men who live upon it. They are as truly and as fully his slaves as though his ownership in their flesh were acknowledged.(5)

I cannot here go into detail about economic justice, but I refer those interested to my recently published book on the subject (6). The short answer, however, is that those who ‘own’ land and natural resources should pay to the community a yearly rental fee, based on the market value of their holdings (irrespective of buildings or other improvements). Such a fund will guarantee landless citizens at least a minimal income, and also pay for the valid expenses of government. More importantly, the community’s act of charging

market prices for land and natural resources will help ensure that the latter are put to their highest and best use, generating more jobs and wealth for all. Additionally, no taxation should exist on productive human activity (such as working, via wage and income taxes; buying, via sales or value added taxes; saving and investing, via income and capital gains taxes; giving, via gift and inheritance taxes; etc.), as that punishes — and hence lessens — good behaviour, while robbing people of the fruits of their labour. From what I understand of recent Indian history, efforts at land reform in the various states have been economically counterproductive, aimed at forcibly subdividing the land itself (7) rather than merely its economic rent. My impression of the Indian economy in general is that central planning and control have effectively stymied individual initiative. But all that is necessary for people to thrive economically is for them to have free and equal access to the earth (or its equivalent in rent) and the rights to free action and free association (ie, to engage in entrepreneurial and free market activity), with the only proviso being that they do not violate the equal rights of others.

The US has, of course, long championed the latter freedoms, but has ignored the injustice inherent in its monopolistic system of land tenure. It was able to escape most of the harmful consequences of the latter for much of its history by virtue of its frontier, which provided a safety valve for oppressed labourers, who could escape wage slavery by homesteading frontier land, thus becoming their own masters. That avenue of escape was gradually eliminated, and the US then took the indirect route of wealth redistribution (via income, estate, and other forms of taxation) to attempt to redress the situation, rather than eliminating the injustice at its root.

As Winston Churchill said, “land monopoly is not the only monopoly that exists, but it is by far the greatest of monopolies. It is a perpetual monopoly, and it is the mother of all other forms of monopoly.”(8) Thus, while many forms of monopoly now exist, and many people make money in partly unfair ways in many fields other than real estate and natural resource utilisation, these other forms would not be possible without the primary monopoly

of land and natural resources. The US and most other countries have thus allowed the privileged to retain their immoral means of subjugating their fellow men. (Not that I believe the privileged are, in general, aware of the partly immoral nature of their means of attaining wealth. If they could perceive the basis of the injustice, so also would most others.) But perhaps the day is coming when the masses will understand the true nature of their plight, and will take proper remedial action.

A proper ethical focus

A primary ethical focus throughout the world must be the establishment of true economic justice, along the lines discussed above. Only in that way will the question of the exploitation of the poor be properly addressed and satisfactorily answered — by the elimination of poverty.

Additionally, most of the world needs to adopt something like the *de facto* (but not *de jure*) system now in place in India, by permitting monetary compensation for organs. Said Henry Hansmann, of Yale Law School: "...this prohibition may be overly broad... It appears possible to design suitably regulated market-type approaches to the acquisition and allocation of cadaveric organs (and perhaps of organs from living donors as well) that will be neither unduly offensive to ethical sensibilities nor easily abused..."(9)

For most of the world, cadaver tissues and organs should be adequate to meet demand. This seems a reasonable assumption, given that Belgium -- which has a policy of 'presumed consent,' in which people are presumed to be willing organ donors unless they have indicated otherwise -- has such a surplus that it is able to supply many foreigners with needed organs (10). And data from the US on accidental deaths, where the death itself occurs in a hospital setting, suggest a potential surfeit of transplantable organs (11). The laws against monetary compensation thus need to be repealed, allowing organ procurement organisations the freedom to use whatever financial incentives are required to bring the supply up to meet demand. (From an ethical standpoint, it would be wrong to use live donors when cadaver organs are available,

assuming that cadaver organs are equally as effective and safe as those from the living. If this is not the case, ie, if cadaver organs stand a greater chance of failing or infecting their recipients than those from living donors, it'd require careful consideration and balancing of the risks to donor and recipient to decide the proper course of action. Nevertheless, it is the individuals involved, and not legislators and bureaucrats, who should make such decisions.)

For most of the world, then, the question of the ethics of living donation will be a peripheral concern, arising only in cases of extreme time urgency, when one simply cannot wait for a cadaver with the proper tissue match to become available. In those cases, live donation, in which the pool of potential donors is much larger, will continue to be the only viable option. For India, however, for a variety of reasons, any large-scale use of cadaver organs is not currently feasible. Thus, for India, live donation will continue into the foreseeable future.

Summary

Given the above considerations, were I a transplant surgeon in India, I would have five relevant ethical concerns:

1. Economic justice: support the establishment of genuine economic justice.
2. Cadaveric vs. living donors: support a transition from a system emphasising living donors to one relying mostly on cadaver organs from those who have suffered brain death.
3. Fair compensation: try to ensure that donors are paid as much as possible (since the current market contains some degree of exploitation, due to the entrenched economic injustice). In practice, this would entail dealing only with organ brokers who treat donors fairly.
4. Do no harm: over and above the usual concerns expressed in the Hippocratic Oath, take all reasonable steps to ensure that patients have adequate follow-up care and legal options for redress of grievances.
5. Legalise organ selling: because the above-mentioned legal options are unlikely to be feasible under a black market

system (lawbreakers rarely wish to attract legal attention to their own "criminal" behaviour), one must seek to remove the laws banning organ selling. Their existence, in an atmosphere in which black market activity nevertheless thrives, not only places those involved outside the protection of the law, but engenders disrespect for law and law enforcement in general, to the detriment of society. More importantly from an immediate standpoint, removing the ban will free the operations from the clutches of organised crime, and make transplants less expensive for recipients, less exploitative of poor donors, and less dangerous for all involved(12).

For anyone seeking further libertarian perspectives on this issue, especially as it relates to US policy, a good source is my website, at www.organselling.com

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The case against kidney sales

GEORGE THOMAS

The philosophers have only interpreted the world in various ways; the point is to change it.

Karl Marx: *Theses on Feuerbach*

I am one of those who, according to Radcliffe-Richards et al, oppose the practice of buying kidneys from live vendors from a feeling of “outrage and disgust.” (1) These feelings are by no means irrational. They are based on a bedrock of moral principle: that no human being should exploit another. The opponents and proponents of the trade in human organs are divided by this (perhaps unbridgeable) chasm – the one side is wedded to the belief that not only are all human beings born free, but that they should stay free; the other is not so sure. The evolution of human civilisation has witnessed several periods of gross exploitation of human beings. Slavery, the extermination of six million Jews, and today the transfer of body parts from one living human being to another, for a financial consideration, are part of a continuum of values which sees some human beings as less valuable than others. It is this value system that those of us who oppose the sale of kidneys, seek to change. All arguments in favour of the trade are attempts to clothe, in the garb of reason, the concept that it is all right to remove a body part from a poor person and put it into a rich one. But even these arguments will not bear scrutiny and I will deal with them below.

First, the argument that the prohibition of organ sales worsens the position of the poor because it removes an option in their already deprived lives: Here the authors (1) of the paper have cleverly stated the most potent contrary argument themselves:

the solution is the removal of poverty. They, however, appear to consider this a distant possibility, and in the meantime advocate the selling of kidneys as one option available to the poor to better their circumstances. It would have been useful if the authors had adduced material to show how and how long this so-called option works. In the absence of any sustained means of livelihood, it is quite probable that the money obtained by the sale of one organ will soon be gone. What shall the seller do next? Sell another organ? An eye? A lung? And when all the paired organs are gone?

Let us accept that the risk involved in nephrectomy is not high. But is it not a fundamental tenet of medicine that the risk must be in the medical interest of the patient? What medical advantage does the donor obtain? Undoubtedly the risk is the same for those who sell and those living donors who do not sell but donate out of regard for the recipient. Radcliffe-Richards et al move from this fact to the inference that therefore there should be no difference between the two groups with surprising facility. What matters here is motive: the implicit coercion in the case of the poor who sell out of financial compulsion. Radcliffe-Richards' equating of the motives of the better off, and comparing the risks of nephrectomy with the risks of dangerous sports can only be described as callous. No one prevents them from campaigning against these sports if they are so moved, but for us activists in the Third World there are more pressing matters than looking after the wellbeing of the jet set. A profile of the sellers would be revealing. It will come as no surprise that they all belong to the Third World. And it will also come as no surprise that besides the wealthy in the Third World, the potential buyers will be from the rich, white, First World and from the petroleum driven nouveau riche! No wonder a veritable industry of philosophers has risen in these countries to justify this horrible practice. And in the honourable tradition of colonialism there will always be locals ready to aid and abet the conquerors. He who pays the piper calls the tune!

Radcliffe-Richards et al (1) seem fixated on the belief that legalising and controlling the trade in human organs will protect the exploited. The situation in other fields shows that this is naive indeed. In Hamburg, legal commercial sex workers throng the

glittering Reeperbahn, while in the sad, sordid, shadowy by lanes the illegal commercial sex workers have no shortage of clients. This in a country where social conditions ensure much closer adherence to the rule of law than is the case in most developing countries, which are the main source of people willing to sell their organs. In India, child labour is a reality. Poverty is the main reason for its existence. The efforts of numerous groups have succeeded in making it illegal. Have they removed an 'option' for the poor? After all, the poor consciously send these children to work. Would it be a good idea to legalise the practice and control it on the theoretical basis that it would improve the lot of these unfortunate children? There are many reasons why such trades will always be open to exploitation. The most potent one is that the victims are poor and voiceless while the beneficiaries are generally rich and powerful.

The argument that organ selling is acceptable because some services are available to the rich, which are not available to the poor, is extremely strange. Do the authors believe that the presence of undesirable practices justifies adding a few more? What will the limit be? Who will decide how many more are to be allowed? No prizes for getting it right. The answer is: the rich and powerful. Permit whatever is in their interest. They can always hire a motley crew of philosophers and technicians to justify it and make it possible.

Why is altruism necessary in organ donation? It is because it will ensure the absence of exploitation. It is nobody's case that unless some useful action is altruistic it is better to forbid it altogether. Altruism removes the profit-making element. It will help ensure that organ transplantation is done in the best possible way and thereby achieve the best possible medical result. It will also ensure that no vital organ is removed from a living person. On the other hand, trade in kidneys definitely puts one on the slippery slope to selling vital organs as documented elsewhere (2). Here, the authors utilise the familiar stratagem of positing and demolishing imaginary weak arguments against their stated position, while ignoring the real and powerful argument.

The authors end with an emotional appeal that feelings of repugnance among the rich and healthy cannot justify removing the only hope of the destitute and dying. A powerful statement indeed, but on whose behalf? Is the only hope for the destitute the sale of body parts? Is this modern form of slavery where one sells oneself piecemeal, as opposed to the old form where the entire person was sold, the only hope for the poor of the 21st century? Or are the authors unaware that there is enough for all, if only the rich were not so greedy? (3). Although they themselves state that the real solution to selling is the removal of poverty, they quickly move on to the reasons why selling is acceptable today. The entire tenor of their article suggests that they are not interested in this the real option. Perhaps it is difficult to push this idea in the West where the dominant paradigm is to maintain the current wasteful level of living, never mind that it is at the direct cost of millions of other human beings living elsewhere. How much easier to go for the soft option of buying kidneys from the poor and making this appear as good for both the seller and the buyer.

As for the dying, it is clear that the authors are not concerned about the poor who are dying, as they cannot afford transplantation and all the costs after transplantation. As for those who can afford transplantation, is the transfer of a kidney from a poor person really the best option? People who have undergone dialysis do not seem to think it such an unpleasant experience, as the authors would have us believe (4). Let us not forget also that transplantation is not the end of the story; but that the patient has to be on lifelong immunosuppression, which is quite an expensive proposition. However, it is true that many who would be helped by transplantation are unable to get an organ. The real solutions lie in popularising cadaver transplantation and increasing the donation rate from the brain-dead, and working on technology to make dialysis cheaper and more (tolerable). Radcliffe-Richards et al state that a vendor will never be a potential donor even after death. This is by no means certain. Methods can be found to increase donation rates from the brain-dead and from cadavers. One has only to see the amazing success of the Sri Lankan eye donation programme to understand what can be achieved. This

is the difficult option but the only sustainable one. Nothing can justify using one human being as an organ farm for another.

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Should brain death be recognised as a clinical end point of care?

SUNIL K PANDYA

The concept of brain death

In ancient times, before the realisation of the importance of the action of the heart and circulation of blood, a person was deemed to have died when he stopped breathing. The reflecting surface of a mirror was held before the face of the sick person. Death was diagnosed when the mirror was not fogged by water vapour present in the breath. Later, irreversible cessation of respiration and of the action of the heart were established as the criteria for the diagnosis of death. In the middle of this century, attention was turned to the brain, which required much more energy than other organs. If its needs were not met for four minutes or more, irreversible damage to it followed. After a variable interval, the other organs failed and the person died. In the interim, there was a dead brain in a dying body.

The term 'brain death' was introduced in 1965 during a report of renal transplantation from a heart-beating, seemingly brain-dead donor. Following the path-breaking paper by the ad hoc committee of the Harvard Medical School and international debate on it, the concept of 'brain death' gained general acceptance.

The development of the science of organ transplantation and the availability of drugs that prevented rejection of transplanted organs by the recipient's body made the concept of brain death attractive. Given that once the brain is dead, death of the rest of the person within hours or days is inevitable, should we not use organs from this person to save other lives? International debates were followed by acceptance of this proposition. This has enabled

transplant units to save innumerable lives that would otherwise have been lost.

The law in India

Unlike the United States of America, India follows the British lead and has chosen irreversible damage of the brain-stem as being diagnostic of death. The Transplantation of Human Organs Act, 1994 (Central Act 42 of 1994), lays down the definition of death thus: 'Deceased person' means a person in whom permanent disappearance of all evidence of life occurs, by reason of brainstem death or in a cardiopulmonary sense at any time after live birth has taken place. It goes on to state that 'brain-stem death' means the stage at which all functions of the brain stem have permanently and irreversibly ceased.

Once brain-stem death has been diagnosed by an authorised committee using specified criteria, the dead person's organs can be removed for transplantation provided legally valid consent for this is available.

Stopping treatment after brain death

Traditionally, once there is permanent cessation of breathing and the action of the heart, all treatment is stopped. Under the Transplantation of Human Organs Act, 1994, it stands to reason that once brain death has been diagnosed, there is nothing to be gained by continuing any treatment. The only rational reason for continuing treatment after the diagnosis of brain death – use of the ventilator, drugs to prop up the blood pressure, antibiotics and intravenous fluids – is to provide time for the transplant teams to get their patients in and ready themselves for the operations to remove organs from the dead to the living.

However, as Mr Bumble observed in Dickens' *Oliver Twist*, at times 'the law is an ass, an idiot'.

Our present dilemma

Should we stop all care once the patient is brain dead?

As Lance Stell points out, to many laypersons (and to some medical professionals too, unfortunately), the term 'brain death'

suggests that there is more than one kind of death ('brain death' and 'cardiorespiratory death'), or that there is more than one way to be dead (in a brain-sort-of-way and in a heart-sort-of-way), or that there are degrees of being dead ('brain-dead' and 'really dead' or 'dead-dead'), or that one might die more than once (first, when one's brain dies and again later when one's heart stops).

He narrates an experience that most of us have also encountered again and again. "Recently, I consulted on a case in which an ICU patient's attending physician, an experienced nephrologist, said the following to her patient's family: 'I am sorry to tell you that your daughter is brain dead. I will keep her on life support for a while longer, I will even order her dialysed again, if you wish...at least until you decide what you want to do.' Not surprisingly, the patient's father asked, 'What are her chances of recovery, doctor?'

"Needless misunderstanding had complicated a tragedy. Since the patient had been diagnosed 'dead' by medically accepted neurological criteria, it was no longer appropriate to refer to the medical equipment attached to her as 'life support.' Nor should the attending physician have offered dialysis. After several hours, the confusion was resolved. All interventions were withdrawn. The patient was pronounced dead (when her heart stopped!)."

This dilemma stems from three deficiencies in the Transplantation of Human Organs Act:

Our legislators erroneously included the definition of brain death in an Act intended to regulate organ transplantation.

Whilst defining brain death, they specified 'by reason of brain-stem death or in a cardio-pulmonary sense' thus leaving ambiguity in many minds. It has not been specified that 'brain death' equals 'death' for all purposes. As noted above, it stands to reason that if I can remove heart, lungs, liver and kidneys from a brain dead person for transplantation into other living individuals; I should also stop all medical care if such a person is not a candidate for the donation of organs for any reason whatsoever. I find hospital administrators unwilling to permit such a step. They continue to hold fast to the old 'cardiopulmonary' criterion for the diagnosis

of death when the brain dead person is not a candidate for donating organs.

This has several harmful consequences. The agony of relations is prolonged for days, weeks or even up to six months till the heart finally comes to a permanent halt and the oscilloscope shows a continuous flat line instead of the P-Q-R-S-T squiggles. In many instances, the family undergoes the severely traumatic experience of seeking opinion after opinion from several consultants in the hope that someone will tell them that further treatment is likely to prove fruitful. The family continues to pay huge sums of money for 'intensive care' of a dead person. A bed in the intensive care unit is locked up by a dead person. Finally, doctors and nurses carry out the charade of caring for a person who is dead and spend time on the corpse that could be spent more fruitfully on other salvageable patients.

Some ways out under the present law

Dr M K Mani, senior nephrologist at the Apollo Hospital in Chennai, has a clearly laid down policy. Once a person is deemed to be brain dead, the relatives are called in and the diagnosis and its implications are clearly explained to them. After confirming that they have understood what has been told, they are asked to decide on the further course of action – donation of organs or stoppage of all treatment. Should they opt for the latter, the legal next-of-kin are requested to put this decision down on the case paper and sign the document. All treatment is now discontinued and the body is handed over to them. If, however, the family chooses to continue care in the intensive care unit till breathing and the action of the heart come to a permanent halt, this is honoured.

A senior consultant in Pune informed delegates attending the annual conference of this Society* in that city some time ago that he proceeds along the same lines as Dr Mani, but takes the additional step of asking the relatives to switch off the ventilator and stop the intravenous fluids. These are unsatisfactory measures in that they do not have the clear sanction of the law. Mr Bumble's observation and the law enunciated by US Air Force Captain Edward A Murphy Jr ('If anything can go wrong, it will.') may yet lead to the prosecution of a doctor by misguided relatives of a

brain dead person. We have been assured by senior judges sitting on the bench and senior lawyers practising at the Supreme Court that should such a case be brought before a court, it will, almost certainly, be dismissed. Even so, the dread of seeing one's name in bold headlines – 'Doctor ABC accused of killing patient' – haunts many minds. Courts are heavily burdened and judgements often delayed by years. The appearance of the line – 'Doctor ABC found not guilty of murder' – as a footnote at the bottom of an obscure column years after the event will prove small compensation for the agony suffered by the doctor and his family.

The permanent solution to this sorry situation

We need a separate Act specifying the new definition of death. This Act should provide details of neurological criteria for death to be used in making the diagnosis. The Act must state clearly that this definition supersedes the older definition of death 'in a cardiopulmonary sense'. Once diagnosis of death is made under the new definition, the patient is, for all intents and purposes, dead. The Indian Society of Critical Care Medicine is ideally placed for bringing about this much-needed change in our law.

Note:

**The Forum for Medical Ethics Society*

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Why our cadaver donation programme doesn't work

HARSHA DESHMUKH

Six years since the passing of the Transplantation of Human Organs Act, 1994, recognising brain death, only 28 cadaver kidneys have been transplanted in Mumbai. Why is our cadaver organ transplant programme in such a sorry state?

The definition of death

Most doctors are uncomfortable with the idea of declaring brain death and hesitate to explain it to deceased patients' families, preferring to wait till cardiac arrest occurs. This is a disservice to those needing organ transplants.

Further, the definition of brain death is specified only in the context of the transplant law. Doctors often interpret this to mean that brain death should be declared only if the deceased's organs will be donated. If not, the person is continued on 'life support' till cardiac asystole. This creates confusion and stress. For example, a family was told that their loved one was no more, and then asked if they would like to donate her organs. When they decided not to donate, they were told the body could not be taken immediately; they were legally required to wait for cardiac arrest to occur. This made them wonder whether the brain death diagnosis was correct, and reinforced their decision against donation.

Systemic flaws

Cadaver transplants have not been promoted by the medical profession. Doctors not directly connected with transplantation programmes have often advised against organ donation, even when families inquire about the procedure. This broadcasts their lack of faith in the medical system. Some nephrologists agree

to transplant from unrelated living donors instead of suggesting that the patient register for a cadaver kidney. Finally, hospital authorities ignore instructions to report brain death cases.

Efforts to promote cadaver organ transplants have also back-fired because of doctors' thoughtlessness. It is important to give the family time to come to terms with their loved one's death before suggesting organ donation, but doctors are known to tell the family about the death and ask them to consider organ donation in the same breath.

Some donor families have wrongly been billed for the donation process. Such lapses harm the programme. The time involved in the organ donation process can be a deterrent, especially in medico-legal cases. A patient was admitted for cerebral trauma following an accident, and declared brain dead. Before the organs could be retrieved the body had to be taken to the police station and then for post mortem. Couldn't post mortems be avoided when the cause of death is not controversial? Could postmortems for patients of donor families be done on a priority basis?

Some families ask for monetary compensation or waiving of hospital charges as a condition to donation. Such incentives could help increase donations. In Spain (with the highest rate of organ donors), the government meets donors' funeral expenses.

Public awareness

Public awareness of brain death and organ donation is low, and most families are exposed to the idea for the first time when a loved one is declared brain dead — a difficult time to discuss consent to donation. The problem is compounded by public suspicion of kidney transplant rackets.

In India, the extended family is involved in important decisions, and may overrule the immediate family's agreement to donation. Some common misconceptions to be tackled are: organ donation is against one's religion, it will cause the family further pain, or the system of organ allocation is biased.

Donors' relatives have been grateful for the opportunity to donate their loved one's organs. Those not given the opportunity

I have regretted that their loss was not mitigated by something good out of the tragedy. Everyone in this position should receive comprehensible information to make an informed decision on the matter.

Recipients' reservations

Most patients needing transplantation are unaware of the option. Renal failure patients are rarely aware of the possibility of a cadaver kidney transplant; they are usually looking for a living donor. Other organ failure patients are dying because no treatment options exist. For those who do register for a transplant, the uncertainties of waiting for an organ can be emotionally sapping. Then, some cannot afford the cost of surgery and post-transplant drugs to be taken lifelong. Patients registered for a cadaver kidney have been forced to decline when a kidney became available because they could not raise the money. Planning is necessary; charitable trusts offer financial help for medical treatment, the government can reduce drug costs, and early enrollment to health insurance schemes can make this treatment accessible to a greater percentage of patients.

In Mumbai there have been no cadaver transplants of organs other than kidneys. So patients needing other organs fear being 'guinea pigs' and hesitate to register for a transplant. They shop around for advice and resort to alternative therapies, in the bargain losing money and sometimes their lives. On the rare occasion when a donor organ is available, potential recipients are not on record. In one case a liver retrieved in Mumbai was used for a patient in Delhi.

We need a body to monitor organ demand and supply, with a transparent protocol for putting patients on the waiting list and distributing organs. This will require support from doctors who identify donors and those who transplant organs, from families who donate organs and from patients waiting for organs. It will work only if people know that it is impartial and in society's interest.

Issues in organ transplantation

B N COLABAWALLA

When we scan the history of human civilisations, it becomes evident that the evolution of ethical concepts has preoccupied philosophers, ethicists, sociologists, theologians, professionals and indeed, all of society. We then have to assume that evolving ethical concepts is deemed as a necessity for guiding individuals and societies with a view to furthering their wellbeing.

To begin with we must be clear as to what we mean by 'ethics', a word often used synonymously with 'morals'. Morals or moral philosophy pertain to the prevailing attitudes, beliefs and rules of behaviour in a given society, are influenced by the thought processes propagated in the environs of the time, and are therefore subject to change. Ethical philosophy is concerned with the analysis of these moral values to offer some guidelines on whether the moral philosophy is appropriate or otherwise.

Ethical value systems and moral principles must be pervasive in all sections of society and particularly in those expected to provide leadership, such as in politics, the administrative services and the professions. A down-gradation in one section can have unwholesome effects on other sections. Witness today the consequences of the low standards of ethics and morals in politics in our country. Medical professionals are a part of society; they cannot stand on a separate pedestal, and must be on their guard against such down-gradations affecting them.

To summarise, ethical philosophy is necessary to evolve principles which aim at preserving those parts of the heritage of human societal structures which have served us in good stead and which further the well-being, integrity and dignity of human beings.

Evolution in medical ethics

We have come a long way from the ethical principles enunciated by Hippocrates. Since then, the Hammurabi Code, the Islamic Code, those laid down by Sushruta and Charaka have evolved down to the Geneva Declaration of the International Code of Medical Ethics formulated in 1947 and amended in 1968, 1983 and again in 2000.

Medical ethics is closely interwoven with societal morality in each era of civilisation and is influenced by philosophical, theological, and scientific advances. Today we are experiencing an unprecedented explosion in science and technology which in turn influences concepts in medical practice. Whilst they have undoubtedly benefited mankind in many areas, they have often been mis-utilised. Medical professionals have become over-dependent on technology, dehumanising medical practice. These advances then pose dilemmas of an ethical, moral, sociological and theological nature.

By its very definition the word 'dilemma' implies that there can be more than one answer to a specific question. We have then to discern between a technology's beneficial effects and those ineffective, even harmful to the individual patient. It may be argued that concepts of ethical philosophy are too abstruse and generalised and may not be applicable to specific instances in which moral philosophy is causing a dilemma. This is a misconception. The tenets of ethical philosophy can be juxtaposed to such specific instances where moral philosophy needs to be critically analysed. This brings into relief what Peck has described as 'code ethics' versus 'situational ethics'¹. Application of the tenets of ethical philosophy can then offer an ethically acceptable and practicable solution for society.

It becomes necessary then to keep up a constant review of our ethical value systems without compromising its basic tenets but taking into considerations economic and societal realities. There are four basic pillars on which our concepts of medical ethics rest today. They are:

Beneficence: this entails that whatever treatment we utilise does not harm the patient. It also demands that any intervention must be

done with the purpose of preventing, removing or mitigating any harm that may have been caused.

Non-maleficence: this means that in the first place we should not act in any way which may cause harm to the patient.

Autonomy of the individual is today universally a well-accepted doctrine. This autonomy must be respected. The days of 'medical paternalism' are gone.

Society has a vested interest in the profession and expects that our actions will be based on social justice and responsibility.

Based on these foregoing introductory remarks, I will venture now to offer some observations on ethics of organ transplant.

Evolution of ethics in human organ transplantation

In 1831, when Jeremy Bentham wrote an essay entitled 'Of what use is a dead man to the living?' he could not have foreseen the advent of modern technology which now makes it possible to transplant human tissues and organs. I mention this to re-emphasise that scientific and technological advances call for a constant re-orientation of prevailing concepts.

Secular and theological thinking has for centuries considered the 'principle of totality' inviolable in order to maintain the total integrity of the human being. Hence any destruction of the human body or its parts is contrary to this principle. However, in the past four or five decades, this principle has been analysed in view of the need for tissues and organs for transplantation, to benefit other human beings. Thus ethical principles have evolved to suggest that transplantation would be within the bounds of ethics if certain criteria are fulfilled, in instances of living donor transplantation. These are:

- The removal of the tissue or organ does not impair the health or functional integrity of the donor.
- The benefits expected to be given to the recipient bear an acceptable proportion to the harm likely to the donor.

- The donation should be altruistic and is given without any coercion or any other form of external pressure.
- The donor must be fully informed of the nature of the procedure and the possible — even if rare — complications. This entails the need for follow-up of the donor's health in the future.
- The views of close relatives such as the spouse or adult children are taken into account.
- There must be no element of commercialisation or exploitation in the donation.

It is not always easy to establish with any degree of certainty that all these criteria were met in an individual case. However, these criteria offer a basis on which we can comprise our ethical principles.

Ethics in genetically-related living donor transplantation

It will suffice here to say in this context that if the criteria for donation enumerated earlier are satisfied, there is ethical justification in accepting the donation. I will still stress that the donor must be made fully aware of the nature of the procedure. His or her psychological make-up should be taken into consideration, as should the views of the donor family. We must, to the best of our ability, establish that there has been no undue coercion. All these require communication skills (which, along with concepts of ethics and the history of medicine, are never imparted to us as undergraduates).

Ethics in non-related living donor transplantation

This form of transplantation raises some specific issues of ethics for medical professionals and grave issues of social morality, since it is inevitably connected with the commodification of human organs. The shortage of donor tissues and organs has encouraged 'market forces' and the commerce in human organs. I restrict my remarks to our country and the experiences in live non-related donor transplantation of kidneys.

The question we need to pose is: can the criteria as laid out for live donor transplantation be fulfilled in non-related donor transplantation?

Take the basic criterion of altruism and its negation by commercialisation. Whilst altruism may be a genuine motive in the rare case, we all know that in the vast majority of cases the motivation is the financial reward. As for voluntariness, what greater coercion can there be than dangling the promise of Rs 30,000-40,000 before a poor donor?

As for informed consent, I wonder if illiterate and economically depressed donors are given full details in a language understood by them, and whether their families are taken into confidence. Informed consent consists of more than a signature on the dotted line. Do medical professionals confirm voluntary informed consent through a personal discussion, and is it duly and faithfully recorded in the case papers?

The other important criterion is that there shall not be any commercialisation or exploitation. Commercialisation is self-evident. Exploitation should be a matter of concern to society. The most lurid is that by the middleman or broker who thrives on the gullibility of the illiterate or on the economic strain of the weaker sectors of society. How much of the sum actually goes into the donor's pocket is a matter of guess work. Then there is the exploitation of the donor's poverty by the rich recipient. It is argued that the poor man needs the money which the rich man has with him to give and thereby a little redistribution of wealth is made. I venture to suggest that it is a redistribution of health from the poor — who can ill afford it — to the rich. The inequity of the situation is surely against the grain of social ethics.

It is argued that individuals are free to donate their kidney for a price, as much as they are free to sell their labour or other services. It is also argued that individuals have freedom of action. There are grave dangers to the moral values of society in such propositions.

The freedom of individuals to behave as they wish is always circumscribed by the needs of the greater good of social morality. The proposition pits a distorted value system of individuals in need

and their methods of obtaining that need against established value systems of organised society. If society accepts the trade in human organs, it will be replacing the concept of the human organism's intrinsic value with the extrinsic value of the human body or its parts, making them a commodity. This destroys individuals' autonomy and dignity. There are also dangers of extortion and even criminalisation, as the recipient's identity may be known to the donor and his family.

In this situation, the dilemma before the medical fraternity is acute when faced with a patient who has no family donors or chances of obtaining a cadaver donation within a reasonable time, and cannot afford chronic dialysis. Do we let such patients die? Do we refuse them a non-related donor transplantation? Out of sympathy for such patients, I would like to evolve a strategy which separates transplantation from the nexus of commercialisation. But I find myself groping in the dark. I am aware that the latest Human Organ Transplantation Act provides for some safeguards, but there are many loopholes. Non-related donor transplantation can be carried out provided all aspects of the procedure are approved by what an 'approval committee'. But who does this committee consist of besides medical bureaucrats? Does it receive advice from lawyers, ethicists, sociologists, psychologists, etc. to help it make its judgements? I am skeptical of that.

A rather novel concept has been floated, of 'rewarded gifting'. I consider this merely a terminological subterfuge. It represents the commodification of human organs while placating professionals. I did not realise that one gives a gift and expects a reward! I find the arguments of protagonists of this concept specious and am unable to find an ethical compromise which safeguards social morality.

Obligation to the recipient and family

Recipients must be fully informed about the nature of their illness. They must be given a choice in the modalities of treatment, namely haemodialysis and transplantation. They must be given a clear picture of the nature of the operation and its likely sequelae, both immediate and long term. Recipients and their families have to be informed of the economics of the treatment.

particularly the need for post-transplant medications which can be expensive. It is distressing to see families face economic ruin on account of a transplant, with the liquidation of all their assets and the compromise of other family members' future. In this context, professionals must exercise extreme judgement in advising transplantation for patients with contraindications to the procedure. They must estimate the chances of success. They must take the moral responsibility of advising the family clearly on the issue.

Ethics in relation to cadaver organ transplantation

It might seem that there are no serious ethical problems in this form of organ transplantation but there are some issues.

There are many theological and religious concepts expressing the inviolability of the human body even after death, in the belief that the body should reach the other world as a whole. However, it has been argued that if we believe in the concept of reincarnation, we are concerned only with the 'spiritual passing away' of life, leaving our physical bodies as empty shells. It would then be within the bounds of ethical principles, both theological and sectarian, to allow such bodies or their parts to be used for the benefit of humanity. Today many theologians of various religions share this view. Still, there will be groups and families who adhere to the stricter religious concepts. Professionals are ethically bound to respect their sentiments when approaching the subject of organ donations.

This brings us to some of the ethical dilemmas in cadaver donation programmes, namely of establishing priorities in the choice of patients to receive a cadaver kidney, as the demand will far outstrip the supply. This will be all the more applicable when one donor matches more than one potential recipient. The question is: what parameters should we employ when excluding so many in need? Is it age? Should a judgement of whether the patient's economic resources will allow for long-term success be made? Is it dictated by the need of the family to have an earning member restored to health? Is it by the importance of the individual to society? Should it be purely on medical grounds? Or shall we make the final choice

by drawing lots? Such dilemmas cannot be easily resolved but need to be addressed.

Ethics in relation to society

Throughout history we observe that the practice of medicine has been closely intertwined with the social, economic and moral texture of society. All advances in medical science have always promised an impact on society. But the medical technological advances of the past two or three decades have been so phenomenal that society is often left bewildered. There is always a time lag between the advent of such advances and the time required for society to absorb their impact. This places a moral and ethical duty on professionals to be explicit in our approach and explanations. We have to help society make what Illich calls 'social assessment of technological progress'². We are an integral part of society and we cannot isolate ourselves on a pedestal by assuming a posture that we are only concerned with our technical perfections and service without reference to social needs and morality. Morality in medical practice has no different dimensions than morality in other sectors of society. The finger that points to lack of morality and ethics in other sectors may also be pointing at us.

The concept of brain death — or more precisely brain stem death — has created problems for society to understand. This places two types of ethical and moral burdens on professionals. They must convince society of the ethics of brain stem death, and if the concept is accepted ensure that the criteria of brain stem death are clearly articulated and scrupulously enforced.

If society expects (and rightly so) medical professionals to maintain high levels of ethical and moral standards in the execution of organ transplantation programmes, professionals will expect that society will also undertake to bear its responsibilities — to mobilise its economic, man-power and other resources for the purpose. It must promote awareness of the issue and the need. It must reorient social ethics on these issues. Society will have to foster and sustain such activities and thereby also act as a watchdog. If society shirks its responsibilities today, it may not have a second chance tomorrow.

I would like at the end of this article to say that the views expressed in this article arise from my personal perceptions of the issues. Let them be debated by society as a whole, and medical professionals in particular.

Notes:

- ¹ M Scott Peck. *The road less travelled and beyond: Spiritual growth in an age of anxiety*. 2nd ed. Touchstone;1998.
- ² Ivan Illich, the modern radical philosopher who critiqued modern education and society in his books like *Deschooling society* (1970) and *Tools for conviviality* (1973)

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Human organ sale: the Kerala story

JAYAKRISHNAN T, JEEJA M C

It has been reported from the Idukki district of Kerala, at Poomala tribal settlement, that 45 persons sold their kidneys and 30 received advance payment for the same. In Kerala, there are 20-80 renal transplantations per month from live donors, mostly done by private, for-profit hospitals (1).

This issue created a lot of commotion in the media and political and medical fields. The Kerala State Health Department closed the chapter after satisfying itself with a cursory enquiry by the police which suggested that 'there is nothing legally wrong in the case records in the hospitals accused'.

In Kerala, 13 hospitals spread over six districts perform renal transplants. Four government and three private hospitals perform only related donor transplants. The remaining six private hospitals do transplants of unrelated as well as related donors. Till October 2002, there were 1,178 renal transplantations carried out in Kerala. Of these, 488 were from unrelated donors. One hundred and thirty-five of 183 transplants performed in the accused hospitals in Kozhikode were from unrelated donors.

Findings of the police enquiry

Sources reveal, on conditions of anonymity, certain conclusions of the 'police enquiry report' which the state government is keeping under tape. Nearly 20 persons, the majority of them poor and uneducated, traded their kidneys for money. Most of them contacted a 'middle man' through whom the transactions were discussed and finalised. They sold the kidney as an option to overcome their immediate financial difficulties. There is evidence to show the involvement of a few doctors. Under the state Act, every transplantation from a live donor who is not a relative of

the patient has to be screened by the Authorisation Committee to ensure that there was no payment involved and the donor is acting with altruistic motives. Although all the cases were approved by the Authorisation Committee there was no evidence of the involvement of any of the members of the Committee (2).

As 'kidney trade' was evident in the preliminary committee sitting, the state branch of the Indian Medical Association (IMA) deployed an enquiry committee on this issue. The draft report indicated large-scale kidney rackets operating in Kerala. An important finding was that a woman donor had undergone a medical termination of pregnancy (MTP) conducted by a lady doctor. But the final report published by the IMA State Committee was 'white-washed'. It found nothing irregular about the kidney transplantations. There were protests against this 'correction' from the IMA itself under the leadership of Dr Mohammed Ali who was the chairman of the Ethics Committee and had conducted the enquiry and prepared the draft. The IMA leadership finally expelled the doctor and the issue was in court.

For years India has been known as a 'warehouse for kidneys' and has become one of the largest centres for kidney availability. To curb the unethical trade of human organs and promote legal transplantation, the Indian Parliament adopted the Transplantation of Human Organs Act in July 1994 (3). It was concerned with the removal, storage and transport of human organs. Brainstem death was accepted as death when diagnosed by a skilled person at the bedside without sophisticated instruments. The law mentions people who are competent to certify brain death and removal of human organs and the hospitals registered for removal, storage and transplantation. This allows removal from related or unrelated cadavers, live donation from first-degree relatives and unrelated persons in case of a dire necessity.

In spite of this law, the use of powerful immunosuppressive drugs and new surgical techniques boosted kidney transplant activities in the atmosphere of loose medical ethics. Many have sold their kidneys to build houses, feed their families and wed their daughters. Many 'kidney tours' and 'kidney marriages' have taken place between people. In 1995, a customs officer of

Delhi uncovered hundreds of 'kidney tours' to foreign countries. In the same month, it was discovered that commercial trade in kidneys occurred among the residents of a leprosy rehabilitative colony in Chennai. Later, the police uncovered a massive racket in Bangalore in which the kidneys of nearly 1,000 unsuspecting people were removed in a leading city hospital (4).

The organ trade within and outside the country is very difficult to prevent among the rich as there are many loopholes and grey areas in the law, and poverty is all too common (5).

No monitoring

Indian law permits live donation from non-relatives; this is mostly misused for commercial interests. The lacuna in the law was that the screening committee had no mechanism to find out the whereabouts of the donor and whether the donor was truly altruistic. In most cases, the donors were well coached by the middle man before the screening procedure. There is no system in place that can effectively monitor the transplantations. If the organ trade is not controlled, disappearances, especially among street children, violence and baby kidnapping rackets may flourish along with the theft of organs of executed criminals in future. The people may lose trust in the medical community and may suspect their involvement in premature declaration of death on seeing a signed donor card (6).

Donation of an organ is most altruistic, meaning an act in life to help another human being and reliably change the situation of the latter. Even in the UK, 70% of the people favour organ donation, but only 25% hold donor cards (5). Data from the Arab world shows that all the 81 renal transplantations conducted during 2001 were cadaveric donations (7). Selling organs demeans human beings; it is always 'the rich who receive and the poor who give' (6).

In India, it is estimated that there are 80,000 people with severe renal failure and 650 dialysis units are available. Our resources are scarce and the needs outstrip these (4). The recurrent annual cost of haemodialysis is Rs 1,00,000 and that of renal transplantation is Rs 75,000-1,00,000 (Dr Pisharody, personal communication,

2002). We have to weigh the risk-benefit, cost-benefit and cost-effectiveness ratio in the management of end-stage renal disease.

A recently published World Health Organization (WHO) document made the following point (8): changed economic policies leading to foreign competition in the health service market are reducing the access to care for the poor. It appears that health is a luxury in developing countries. The system of forcing individuals to make out-of-pocket payments for health care denies basic care to the poorest members of the society. The above statement is relevant in the Indian context where there is no social security system and very little public expenditure in the health sector.

Studies have shown that 85% of doctors in India have no training in medical ethics (9). Teaching, training, following and practising ethics among doctors in our country is the only solution for the unethical medical problems flourishing in our country amidst poverty. We have to uplift the four big values in bioethics: autonomy, beneficence, non-maleficence and distributive justice.

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Ethical dilemmas in living donor liver transplantation

A S SOIN

Liver transplantation is accepted worldwide as the only cure for terminal liver failure. Although the recent tragic death of a liver donor at a hospital in Delhi underlines the need for caution, a knee-jerk reaction to liver transplantation or liver donation is inappropriate.

In Asian countries where cadaveric donation is practically non-existent, living donor liver transplantation (LDLT) is the only viable way of performing liver transplants in reasonable numbers to treat patients with end-stage liver disease. However, several ethical issues need to be addressed before a hospital embarks on a LDLT programme and indeed, before every such transplant.

The most serious objection to LDLT is the violation of the principle of non-maleficence, or to do no harm. The donor is at risk from a lengthy and potentially dangerous surgical procedure without accruing any health benefit. It is unethical to perform LDLT at a centre with sub-optimal facilities or expertise. The minimum requirements to start LDLT should be set out by the Indian Society of Organ Transplantation, ratified by established foreign teams and followed rigidly by all new centres.

Donor issues: coercion, consent and acceptable risk

There is concern about whether live donation can ever be without emotional or financial coercion. While emotional pressure has been more or less accepted or overlooked, financial incentive is illegal. Although donation should be motivated only by altruism, the real reason behind it is difficult if not impossible to determine. Some have lobbied for paid donation but the transplant community at

large has been strongly opposed to it due to the danger of abetting exploitation of the under-privileged.

If the family of the prospective recipient is considered to be one ailing unit, donation by one of its other members (a first-degree relative or the spouse) may be justifiable since the family accrues a benefit for a calculated risk. However, this argument cannot be extended to unrelated donation.

Genuine informed written consent is central to the safe and optimal use of LDLT. However, even if every detail is given, the understanding of prospective donors will vary with their level of awareness, and social and educational background. An overzealous and detailed description of possible complications can be misconstrued, putting off donors needlessly due to ill-founded fears and denying the recipient a chance to live. While we explicitly inform all our prospective donors (and their kin) about the mortality and major morbidity, we tailor the details of the explanation according to the perceived level of their understanding.

Some centres take informed consent in two sessions, spaced apart, to enable the donor and family to ponder over the pros and cons without time constraints (1). Although we do not do this in two defined sessions, our policy is to inform the donor of all possible consequences over three-four counselling sessions in the outpatient clinic, and then take informed written consent before the operation.

To avoid bias, it has been suggested that donor evaluation be done and informed consent be taken by a physician who is not from the transplant team (1). However, we believe that only a doctor from the transplant team can evaluate and inform the patient with the correct perspective and should be the one assigned this task in good faith. Detailed psychological testing is essential to ascertain the donor's willingness to donate the organ free of coercion and also enhance his/her understanding of the various psychological issues. Finally, the relationship between the donor and the recipient, and the non-coercive nature of the donation, must be confirmed by a government-approved, non-partisan authorisation

committee before the transplant is permitted.

It is well established that liver donation is safely possible because of two unique qualities of the liver - reserve and regeneration. Due to its enormous reserve, a person is able to function normally with as little as 25% of the liver. Within a few weeks, the liver actually regenerates to its normal (pre-removal) size (2).

Still, in spite of careful preoperative work-up and the best surgical techniques, there remains a very small risk to life (0.3%) from donor hepatectomy (3). The risk is higher in a right lobe donation than in a left lobe one. The risk of donor hepatectomy may be higher than non-donor hepatectomy since removal of the diseased liver leaves behind much more functional liver than does a donor hepatectomy. A small risk is expected in any major surgery. This risk may seem justifiable for the family in which a terminally ill person is restored to normalcy. However, there remain detractors from this view.

Recipient issues: use of scarce resources and deciding priority for transplant

Even when cadaveric donors are available, there are ethical dilemmas over the use of a scarce national resource for patients who may have inflicted the primary disease or a co-morbid condition upon themselves (alcohol- or paracetamol-induced liver failure), those who may not have prolonged survival after transplantation (those with hepatocellular carcinoma or AIDS), those who may not be 'useful' working members of society (elderly recipients), and those who are not likely to have good graft survival (those with recurrent hepatitis C). The successful use of partial livers obtained from living donors can reduce waiting periods and mortality, and also offer a choice of transplantation to the above categories of patients who may otherwise be deemed to be low priority candidates due to societal or ethical considerations. In this way, they do not compete for the limited national pool of cadaveric donors. However, whether healthy donors should be put to risk to benefit this medically sub-optimal group of recipients is open to debate. Most centres would accept this risk.

Recommendations

- The first priority of the transplant team should be to ensure the well-being of the donor and exclude a person from donation if he/she is not an optimal candidate.
- At the hospital level, detailed psychological assessment and an interview with an impartial authorisation committee are essential to enhance the donor's understanding of the various psychological issues, confirm the relationship of the donor with the recipient and ascertain the donor's willingness to donate free of coercion. Detailed written informed consent must be signed by the donor before surgery.
- All recipients considered for compassionate transplants outside the accepted clinical criteria should be approved by the hospital's ethics committee.
- A regular medical audit should be routine in all hospitals. All centres should send all donor data to donor registries at the national and international levels.
- The State and National Departments of Health should empower the Indian Society of Organ Transplantation to prepare LDLT guidelines in concordance with international norms, which must be rigidly followed by all centres. These should cover the minimum requirements for a team to perform LDLT; maintenance and submission of detailed records of recipients and donors for all transplants; unrelated and non-directed donation; donor compensation and a definition for acceptable donor risk.

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Living donor liver transplantation

A V SRINIVAS

There was some debate within the editorial board about the appropriateness of carrying the following exchange in an ethics journal. At one level it is a 'complaint' from a patient's relative and an institution's defence of the allegations. However at another level, the story raises some larger issues which are relevant to contemporary ethics.

The field of organ transplantation is no stranger to ethical controversy. A particularly complex issue involves living related transplantation where a healthy donor is at some risk, including the risk of death. In other words in an attempt to save one life, two lives can be lost. It is obvious that such a potentially dangerous situation needs the highest level of informed consent. And if things do go wrong there must be a sound and transparent mechanism for dealing with the situation.

This journal has previously carried an editorial on the issue of living related liver transplantation.

This unfortunate incident also points to the potential danger of an increasing trend, in the globalised world, of foreign doctors performing procedures and flying back leaving their local counterparts to face the complications.

Hence we finally decided to put before you the story of a family bravely facing a tragedy of immense proportions. It also highlights the problems of high technology medicine where high-risk, complicated and costly procedures are marketed and performed with a promise of cure.

Mr AV Srinivas wrote to IJME describing his parents' experiences. Mr Srinivas' father was diagnosed as suffering from liver failure

and advised a liver transplant. The transplant was carried out in April 2003, in Global Hospital, a private hospital in Hyderabad. The donor was Mr Srinivas' mother. The transplant was done by a team of surgeons headed by Dr Nigel Heaton and Dr Paolo Mueisan from King's College Hospital, UK. The Global Hospital team included Dr Kancherla Ravindranath, managing director of Global Hospitals and head of its department of surgical gastroenterology, Dr Dharmesh Kapoor, hepatologist, Dr PBN Gopal, anaestheologist and intensivist, Mrs Lalitha Raghuram, chief liver transplant co-ordinator, and the support staff.

Mr Srinivas' father died within two weeks of the transplant, in the hospital ICU. His mother suffered a cardiac arrest within 48 hours of the surgery and has been in a persistent vegetative state since then.

Mr Srinivas feels strongly that the hospital and staff behaved unethically in promoting adult-to-adult live transplants without the necessary experience. The hospital and staff did not indicate that adult-to-adult live liver transplants are more risky than those from adults to children. Further, Mr Srinivas states that he was not made aware that this was the first adult-to-adult live donor liver transplant in India. Finally, he notes adult-to-adult live donor liver transplants are not permitted within the UK National Health Service (NHS) because of the risks to the donor. King's College, with which Dr Nigel Heaton and Dr Paolo Mueisan are associated, is part of the NHS. Such transplants are done in the UK only in the private sector, mostly on foreign nationals.

Mr Srinivas provided IJME with replies to letters he wrote to the BBC, the UK General Medical Council and Professor Roger Williams, director of the Institute of Hepatology, Royal Free and University College Medical School. The BBC's reply notes that it had a policy of not releasing untransmitted footage but would consider his request if he would indicate what was contained in the footage that might be of his interest. The GMC replied that his complaint had been forwarded to Drs Heaton and Mueisan. Professor Williams indicated that adult-to-adult live donor transplants are not done in the UK under the NHS, but UK doctors do make this available in the private sector, mostly to people from

outside the UK. He added that as a person working with the doctors named, he could not comment further but suggested the names of others who could.

The following account is based on Mr Srinivas' statement as well as some documents sent by him.

Editors

My father's health problem – cirrhosis of the liver -- was identified in late 2001. Over 2002, we visited Dr Nageshwar Reddy at the Asian Institute of Gastroenterology. Dr Reddy spoke about the transplant option but said the success rate was not good in India.

Towards the end of 2002, we saw media reports that experienced liver transplant surgeons from King's College Hospital, UK, would be doing liver transplants at Global Hospital, Hyderabad. In December 2002 we visited Global Hospital for the first consultation with Dr Dharmesh Kapoor of Global Hospital, who told us to continue the previous medication with a few changes. We were told that Dr Mohammed Rela, a liver transplant surgeon from King's College, UK, would be visiting Global Hospital and took an appointment with him. Dr Rela examined my father and also went through his medical records. He said the only option was a liver transplant, and that he was a suitable candidate. Dr Kapoor and Dr Rela said many transplants were being done in the West and that in the UK they had a good success rate.

In early March 2003, we consulted Dr Hector Vilca Melendez, also of King's College, during his visit to Global Hospital. This was shortly after the media reported on the first liver transplant done there, by Dr Melendez. Dr Melendez went through the medical history and told us transplant was possible, and described the success rate in the UK. We discussed the matter again with Dr Dharmesh Kapoor and on his advice my father went for pre-operative investigations for which we paid Rs 95,000.

On March 28, 2003, Mrs Lalitha Raghuram, chief transplant coordinator in Global Hospital, who also heads the Hyderabad branch of the MOHAN foundation (an NGO promoting organ

donation/ harvesting), called us to say there was a prospective (cadaver) donor available. She asked us to make a deposit of Rs 10 lakh immediately, and indicated that the surgery could be done any time, as the surgeon from the UK was in Hyderabad. She also said that unless the patient was operated upon immediately, his condition could worsen and he could become unfit for surgery. We borrowed the money from various people and deposited it but then we did not hear anything more on the matter. Some days later, we were informed there was a cadaver liver available in Chennai. We were told to decide within half an hour if we could pay Rs 7 lakh for the chartered flight from there. We said we could not afford it.

In the meantime my father's health deteriorated and we took him back to the hospital. This was when we were first advised to consider a live donor transplant, from a family member. My mother was counselled. My parents did not consider my brother or me as potential donors, I suppose because of our career and marriage future.

I do not have any documents on the informed consent process. Family members were also spoken to, but I do not recollect much counselling. They explained that the donor's liver would grow back to normal size within two weeks, and she would be back to her normal self in 4-6 weeks. They did not describe any risks. They did not mention the difference in risk between an adult-child live liver transplant and an adult-adult live liver transplant. They used the term 'live liver transplant' only.

They also said the search for a cadaver liver would continue and if it were found the live donor transplant would be cancelled. We were also assured that we would not be charged for the donor's expenses and my mother was asked to undergo investigations. My mother was hesitant but she saw this as my father's only hope. She was found to be fit for the transplant.

The surgeons were Dr Nigel Heaton and Dr Paolo Mueisan of King's Hospital, UK. Dr Heaton checked on my mother before the surgery. He said it would be major surgery for the donor – this was the first time we heard the word – but that everything was fine. He also said he had done about 55 live liver transplants and none

of the recipients had died. The doctors also said my father was in good shape for surgery and would survive the operation. No one used the term 'adult to adult live donor liver transplant'. They described it as 'live liver transplant'. We did not know that there are different success rates – and risks -- for partial liver transplants from live donors and total liver transplants from cadavers. Dad's was the third liver transplant at Global Hospital; the previous two were cadaver transplants.

In the early hours of April 22, 2003, both our parents went into the operation theatre. We were told the surgery went well. It took 22 hours. Then on April 24, within 48 hours of the surgery, my mother had a cardiac arrest in the ICU. By the time they got her heart beating again, she had suffered brain damage. We believe this happened because a delay in resuscitation led to irreversible brain damage. They kept telling us that she would recover, but the extent of damage could not be known until she regained consciousness. It is now more than two years.

My father died in the ICU within two weeks of surgery. The death report, signed by Dr PBN Gopal, anaesthetist, states that the cause of death was multi-organ failure due to fungal septicaemia. We believe that he was operated upon when he was unfit for surgery.

A team from the BBC had accompanied the UK doctors. They interviewed my parents before the surgery; they videotaped the surgery and also interviewed the family after the surgery. The hospital and BBC termed it the first Indian related live donor liver transplant (my parents are related). The BBC team left a few hours after my mother went into a coma.

The UK doctors are aware that my father died within two weeks of the transplant and that my mother went into a coma. One of them was there when my father passed away. Neither of them has called back to ask how she is.

We had been told that the total cost would be Rs 12 lakh. In March 2003, we paid Rs 10 lakh and another Rs 95,000 in pre-operative tests for my father. The doctors indicated that they would not charge for the donor's expenses. When she was being taken into the operating theatre we were asked to sign a form committing

to pay Rs 23 lakh, including donor expenses. We objected but Mrs Lalitha Raghuram advised us to sign so the surgery could proceed, and this would be settled during the final billing. Even as our parents lay in a coma we were repeatedly pressurised for the payment, including with threats that medication would have to stop. Later they indicated that they would bear the cost of treating my mother. In January 2005 they sent us a bill of Rs 45 lakh, towards the cost of mom's treatment for the previous 20 months.

Did the Global Hospital have staff skilled and experienced to perform the surgery and advise the patient's family on whether the patient is suited for the transplant? I believe that they advocated a complicated and expensive surgery without giving the family sufficient information on the risks associated with the transplant, especially for adult donors.

In the US, there are regulations and some action is taken when things go wrong. Should hospitals in India here not have the same level of scrutiny?

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Response: Living donor liver transplantation

M VEERA PRASAD

Several patients are dying in India because of the lack of a world-class facility for liver transplant. There had been instances of Indian patients waiting for their turn to receive an organ abroad. Organs are allotted to foreigners only when resident nationals are not suitable. Hence, with the noble thought of helping Indians waiting for organs, Global Hospital put out an advertisement to benefit end-stage liver disease patients and then sought registration of patients. The Global Hospital is well equipped with state-of-the-art facilities. Global Hospital doctors involved in liver transplantations are well trained in the UK. The hospital follows the King's College protocol for liver transplants. To enlighten the public and doctors about the availability of the facility, we advertised in newspapers. As a result we received several inquiries from patients and doctors. There is no need for the hospital to promote anything unethical. We will do everything in good faith.

Mr Jagannathan was a patient suffering from end-stage liver disease (due to alcoholic liver disease). He was in a very bad condition and terminally ill. He was under treatment with doctors in another hospital. He had been advised liver transplant by another doctor in 2002 itself. As mentioned by the other doctor, probably during that time the results were not so encouraging. Precisely for that reason we started the transplantation programme by taking the help of the world-renowned liver transplant team from King's College Hospital, UK, which does about 200 liver transplants a year.

Mr Jagannathan approached Global Hospital for further management in December 2002. He was put under the treatment of a hepatologist and other concerned doctors were closely monitoring

the case. As he was deteriorating, the liver transplantation option was thought of.

Initially, cadaver liver transplantation was discussed with the patient and his family members. As the patient's condition was fast deteriorating, the family members were also given the option of live liver transplantation, as a last resort. Mrs Prameela, wife of Mr Jagananthan, had come forward to offer part of her liver. She was counselled thoroughly, and all problems and implications were discussed with all family members. Meanwhile, a cadaver liver became available at a far-off place. We discussed, with family members the option of getting the liver by arranging a chartered flight. But as the family members were not interested, we could not do the cadaver liver transplantation.

The doctor's team explained everything thoroughly and in detail to the patient and to all family members. We have a very good 'transplant co-ordination' department, which explains the process in detail to the family members including the patient. In transplantation surgeries, unlike other surgeries, we counsel the patient, spouse, close relatives and friends. Without counselling, we do not undertake even a small procedure.

Apart from that, Dr Mallikarjun, son-in-law of the patient and a general surgeon with an MS qualification working as assistant professor in a reputed government teaching hospital, is the main spokesperson of the family. How can a surgeon say that he is not aware of the risks and complications of a complex surgery like liver transplant? It is highly absurd to say that the family members were not informed about the high risks involved in adult-to-adult liver transplants. The internet-savvy family members had equipped themselves with all the information on liver transplants and in fact discussed the implications of liver transplants with us. The allegation is baseless. Feigning ignorance about the major and most complex surgery planned for their parents is an afterthought. Global Hospital follows all rules and regulations very strictly and does things ethically only.

The UK National Health Service (NHS) may not be doing live adult-to-adult liver transplants for its own reasons. Guidelines of

the NHS dictate the King's College Hospital policies, but adult-adult liver transplants are being done in the private sector, in the UK. Even in India, some procedures may not be done in the government sector but are done in the private sector. The private sector takes up challenges because of its expertise, facilities, technology, etc.

The main surgeon, Dr Nigel Heaton, is a world-renowned liver transplant surgeon and had done about 21 such live adult-adult transplants, and a total of about 1,000 liver transplants, before doing it here. Dr Paolo, with good experience, assisted many cases.

Professor Roger Williams heads the unit in the private institute where these transplants are done by Dr Heaton's team. He refers to the high calibre of Dr Nigel Heaton. This itself shows Professor Williams' faith in the team as he is allowing them to operate on his patients.

We did not invite the BBC team to record the liver transplant. The BBC was engaged in producing a documentary on Dr Nigel Heaton. The team came here and shot the liver transplant programme with the permission of the family members.

Once a patient is willing to undergo transplantation, as per hospital policy, the patient has to pay Rs 95,000 towards the pre-operative work-up. The work-up was done as all family members including the patient had given consent for it, after understanding the problems, complications, pros and cons, etc. In our usual practice, we cannot initiate the transplant process until the patient makes some financial commitment, as the liver transplant involves lots of activities/ commitments from the hospital side. As a cadaver liver may be available at any time, transplantation has to be done on an emergency basis. That is why we collect an advance from the patient. After all our vigorous, but unsuccessful efforts to get a cadaver liver organ, we discussed live related liver transplantation as a last option as the patient's condition was deteriorating fast. All the pros and cons, complications to the patient and to the donor, were explained to the family. Only after a thorough explanation patient/family members gave consent. After obtaining valid

consent the surgery was performed. We indeed waived the donor surgery charges, investigations etc on humanitarian grounds (but not the charges for complications, if any, which might arise)

We discussed adult-adult live liver transplant, in detail, with all the concerned family members. The patient's son-in law is a general surgeon. He was the main person and represented the family. The allegation that we said the search for a cadaver liver would continue and if cadaver was found the live donor transplant would be cancelled reveals that the patient and his family had been explained about both options. This means they had been thoroughly counselled about all options.

Mrs Prameela, the donor, was not hesitant. Dr Anurag Shrivasthava, the psychiatrist who examined her during the pre-operative work-up, certified her fitness. It was very clearly mentioned that she was very strong in her decision to donate a part of her liver to the husband. This shows they are hiding the facts.

Mr Jagannathan was in end stage liver disease and terminally ill. He was prepared/stabilised to the best possible condition for surgery. He was never in good shape. They opted for live related transplant because he was deteriorating fast. He survived the surgery. If the patient was unfit, he would have died on the operation table itself or during the immediate post-op period. Everybody knows that liver transplantation surgery is a most complex surgery. It is a false allegation that they heard the words 'major surgery' for the 'first time' just before the operation. He lived for two weeks after surgery. The donated liver worked well; it was not rejected. He did not die of a surgical complication. Surgery was successful but later he died of sepsis, which is one of the commonest causes of death in post-liver transplant cases all over the world, as patients are kept on immunosuppressive drugs to prevent graft rejection.

We did explain that the donor's liver would grow back to normal size within two weeks, that and she would be back to her normal self in 4-6 weeks. And it usually happens. Her liver after donor surgery attained optimum size and even today her liver is working normally. There is no failure of donor surgery.

The donor was kept in the Liver Intensive Care Unit, after surgery. This is a fully equipped, ultra-modern facility. Trained and highly skilled nursing professionals and intensivists are there round the clock to take care of any complications. The donor had a cardiac arrest, which may happen in some patients, especially in the post-operative period. Our doctors and other team members immediately attended on her and resuscitated her. Because of the immediate attention, she survived the cardiac arrest. But unfortunately, because of ischemic hypoxia of the brain, she slowly slipped into a persistent vegetative state. All the reasons for the cardiac arrest have been explored, but no conclusion could be made. This is quite unfortunate but there is no medical negligence as they allege.

The main UK doctors who performed the surgery were here to manage the immediate post-operative period. The second UK surgeon was here for about one month. It is all teamwork. The UK doctors enquire about her health status, even today and we are apprising them. We also consulted some very good neuro-physicians and others, and continued the treatment as per their suggestions. Recently the complainants brought a renowned senior neuro-physician of their choice to examine their mother. He was highly satisfied with our treatment. She is receiving the best treatment, he pointed out. That much special care is being bestowed on her. Because of our best treatment, she is still surviving. It is one of the good examples of teamwork and untiring efforts in patient care.

It is a false allegation that they did not know there were different success rates and risks for partial liver transplants from live donors and total liver transplants from cadavers. There is nothing to hide. In transplantation surgery, there is no money to be made. It is a highly cost-intensive procedure. With the noble intention of giving a 'second life' to the needy, Global Hospitals started the programme. Many hospitals have not started the programme because of the cost implications.

Transplantation is not new to us and the results are good. We are doing different varieties of liver transplantation, such as cadaveric, live related (adult-to-adult and adult-to-child), split

liver transplant, etc. Prior to this case, we did two cases and both are doing well. So far, we have done 21 liver transplants of different kinds and 18 survived. Our success rates are on par with those of the best hospitals in the West.

The usual package is Rs 12 lakh and approximately Rs 3 lakh for blood products (at actuals), and extra costs at actuals, if any complication occurs. They paid only Rs 10 lakh before surgery. We did not insist on their depositing the entire amount. We have not charged the donor's surgery and investigation expenses. It is another false allegation that when the donor was being taken into the operating theatre we asked the relatives to sign a form committing to pay Rs 23 lakh, including donor expenses. Why would we undertake the surgery if they were supposed to pay another Rs 23 lakh? Regarding the allegation that we pressurised them for payment, this again is false. We never told them that we would bear the cost of treating their mother. Everything has been done ethically. We neither pressurised them to pay the bills nor threatened to stop medication. We are treating the case on humanitarian grounds. The fact that we issued the bill in January 2005, nearly 21 months after initiation of treatment itself, establishes that we never exerted any pressure. In fact, we issued the bill at their request, unaware of the fact that they had filed a case in the AP Consumer Forum.

The hospital has highly skilled and reputed doctors, many of them trained in world-renowned centres. The facility and infrastructure are on par with the best in the world. We have done liver transplants with success rates on par with those in the West. Some patients for liver transplantation have come from abroad, after enquiries in different parts of world. We did our first heart transplant on February 6, 2004, and the patient celebrated his 'first re-birthday'. We are one of the major centres for kidney transplantations, both live and cadaver. We did our first bone marrow transplant. Now, a patient from the UAE is waiting here for her lung transplantation, which again will be the first of its kind. We are also planning to do the 'first' small bowel transplantation and the first pancreas transplantation. The hospital has a good reputation

for transplantations. With mala fide intentions they are making false allegations to besmirch our reputation.

It is unethical to say that we advocated a complicated and expensive surgery without giving the family sufficient information. Can anybody believe this? Extensive counselling was done not only to the patients and also to all the family members. They are highly educated and knowledgeable. The main spokesperson of the family, the son-in-law, is a practising general surgeon who does a number of surgeries daily. These surgeries have to be performed after explaining to the patients all complications and after obtaining their consent.

Not only in the US, in India also a regulatory system exists. As they filed a case in the consumer forum, we have given all records to the court for scrutiny. They filed a case in the police station. A state government committee has scrutinised the records and taken statements from us. Mr Jagannathan's body was subjected to post-mortem examination. We are ready for any 'scientific scrutiny'. We are co-operating with all the appropriate agencies. We have submitted the medical records to the General Medical Council, UK, as per their request. They have made false allegations against Global Hospital in the media to get public sympathy to exploit the situation and to damage our reputation. Ethics should be followed by all. In spite of this, we are still providing the best possible care to the patient.

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Asia's organ farms

AAMIR M JAFAREY, GEORGE THOMAS, AASIM AHMAD,
SANDHYA SRINIVASAN

Recent press reports of kidneys being bought and sold in Tamil Nadu (1) only brought to general notice what many doctors and nearly all patients with kidney failure already know: one can buy a kidney in Tamil Nadu or, for that matter, in many parts of this subcontinent. While the kidney trade has been written about *ad nauseum* over the last 15 years, recent developments necessitate a review of the issue. Lessons from the ineffective Indian law against organ sale, and reports from Iran which has a regulated system of compensating for donations, could benefit those in Pakistan who are moving to enact a law on organ transplant, so that the law will ensure ethical practice.

The development of renal transplant as treatment for end stage renal disease was a landmark. However, transplant patients must be on immunosuppressive therapy for life. This means that renal transplant is an option only for the well-off and only financially secure patients will seek a kidney. It is also obvious that only the financially desperate will seek to sell a part of themselves.

The Transplantation of Human Organs Act (THOA), 1994 (2), was supposed to promote cadaveric organ transplantation in India. This has not happened for many reasons: the inclusion of loopholes either by design or default permitting the continued sale of kidneys (the proviso that a person not related to the patient could donate a kidney by reason of "affection" and the inclusion of the spouse as "near relative" so that people can marry for organ "donation"); the availability of enough poor people ready to sell a part of themselves; a social ethos which permits justification of the trade as "good for both – the seller and buyer"; a medical establishment willing to participate and, perhaps most importantly,

a near absence of commitment on the part of Indian society to promote cadaver organ transplant.

The THOA mandated an authorisation committee to ensure that non-related “donors” donated out of affection. This fig leaf of respectability given to the loophole permitting unrelated “donations” was removed when it became clear that the authorisation committees were packed with government representatives, and they had no infrastructure to enable them to verify the averments of the “donor”. The authorisation committees, therefore, only gave a cloak of legality to the continued sale of kidneys by the financially desperate.

A number of changes are needed in law and practice before the original goal of promoting a cadaveric transplant programme can be reached (3).

Is it okay to sell a kidney?

It is worrisome that some in the medical profession argue that regulated organ sale provides subsistence to those who have nothing to sell but their body parts. A follow-up of paid “donors” (4) found that most were financially worse off and their health had worsened as well.

The common social ethos in this part of the world, based on caste, class and other distinctions, still is that some people are less equal than others. Thus many doctors feel no compunction in being part of the racket. As long as they are not directly implicated they will perform live donor organ transplants, with no questions asked. Investigations, reported widely in the press, have also documented the active involvement of doctors and hospitals in the trade.

Can cadaver donation develop alongside paid donation?

Activists who worked for the enactment of the THOA did so in the hope that the law would make organ harvesting from cadavers possible (5). These hopes have been belied. Very few organs have been harvested from the brain dead. It has been pointed out that in a privatised medical system the diffusion of specific medical technologies may be influenced by their scope for making quick profits (6). The dynamics of a privatised medical system – which

includes medical tourism, actively encouraged by the government – will encourage live rather than cadaveric donation.

The transplant industry in Pakistan

If doctors and hospitals in India defy the law against organ trade, in the absence of any legislation on organ and tissue transplant Pakistan has a booming transplant industry (7) which has grown after the Indian law was passed. In 1991, 75 per cent of kidney transplants in Pakistan were from live, related donors. While accurate figures are not available, that proportion is believed to have been reversed today. Over half of these are believed to be on foreigners; the organ transplant industry depends on medical tourism. According to drug company representatives, at least seven transplants take place every day in Lahore, and five in Rawalpindi, mostly on foreign patients. A minimum of 4,000 kidney transplants take place in the country every year. Hospital websites used to carry details of the total cost of the kidney transplant package, but these have recently been removed, apparently in anticipation of a legislative ban.

Cadaver donation in Pakistan

India's THOA permits the removal of organs from a person certified brain dead, after obtaining consent from the next of kin. In Pakistan there is a lack of consensus among Islamic scholars on cadaveric donation. Though Saudi Arabia and Iran permit cadaver donations, there is no law in Pakistan specifically permitting cadaver donation, and there have been only two cadaver donations in the country to date. In the absence of a definition of brain death, taking organs from heart-beating but brain dead individuals could be challenged in court, and informal reports suggest that hospitals have avoided promoting such donations because of the possibility of lawsuits.

The Human Tissues and Organs Transplant Ordinance, 2007

The situation could change with a well-drafted law and indeed for some years legislation has been discussed, if not introduced. Last month, even as a bill to curb the organ trade was to be tabled in

the National Assembly, the Pakistan government introduced the Human Organs and Tissues Transplant Ordinance, 2007, reportedly to bypass the bill. Those who have had an opportunity to read the ordinance have stated that it contains many flaws. Some of these: relatives by marriage are permitted to donate; those nursed by the same woman are considered relations by blood; unrelated organ donations are permitted under some circumstances, and there is a mention of compensation for organ donation. The ordinance even proposes a regulated pool of “voluntary” donors. The evaluation committee which is meant to ensure that transplants conform to ethical practice consists of a surgeon, a physician and a “community notable” – at least two out of three could benefit from paid transplants. The section on efforts to promote cadaveric transplant is also said to be flawed (8). Clearly Pakistan’s organ trade mafia has been able to influence those who drafted the law.

In this context, one can look at Iran where a government-run system pays unrelated donors, thus eliminating the middle person. It has been argued, even by advocates of a cadaveric programme, that the system is fair and not exploitative; both rich and poor have access to transplants, and the donor must be of the same nationality as the recipient (9). However, reports suggest that paid donors in a regulated, legal programme are no better off than those in unregulated markets such as in India (10). And while the waiting lists have reportedly gone, only 10 per cent of transplants are from deceased donors. Will regulated compensation impede the development of a cadaver-based programme in Iran?

Asian organ market?

As many countries of Asia offer themselves as the physicians and surgeons of the world, leveraging their lower human resource costs, there is a real danger that the poor of this region will become organ farms for those who are better off. Health professionals and activists must raise public awareness to promote cadaveric transplant programmes, and prevent what is currently illegal and still underground from being given the garb of legality and social respect.

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Working towards ethical organ transplants

SUNIL SHROFF

The sale of kidneys is a regular scandal in India. A recent expose of yet another racket in the sale of kidneys in Tamil Nadu involved persons affected by the December 2004 tsunami. When some of them did not receive the money they were promised, they complained to the police (1). This is one more example of coercion and exploitation of people who are poor and of the inability of the law to protect their interests.

The Transplantation of Human Organs Act (2) was passed by the Indian parliament in 1994 and subsequently ratified by the state assemblies. It accepts brain death as a form of death and prohibits commerce in organs. It limits the donation of organs without any legal restrictions by only the first relatives (mother, father, brothers, sisters, son, daughter and spouse) of the recipient. By accepting brain death as a form of death, the law was expected to use a large pool of patients for organ donation and overcome the shortage of organs, especially of kidneys. It was also expected to help develop other critical solid organ transplant programmes such as of liver, heart, lungs, and pancreas.

Since the Act was passed approximately 1,200 transplants have been done of various organs that were sourced from this pool; however donations have been sporadic and the numbers have not been able to cater to the demand for organs (3). This has resulted in a thriving trade involving commercial donors and middlemen. In most instances media reports have also indirectly pointed a finger at medical professionals. In a few instances the media have caught doctors unaware by using a hidden camera. Rarely however, have any direct allegations been made.

Factors promoting the trade in organs

Two central issues related to the trade in organs need to be addressed: the effectiveness in implementing the current law and the financial compulsions that make people donate their organs.

Sub clause 3, clause 9, chapter II of the Act gives room for unrelated transplant activity. It states: "If any donor authorises the removal of any of his human organs before his death under sub-section 1 of section 3 for transplantation into the body of such recipient, not being a near relative as is specified by the donor, by reason of affection or attachment towards the recipient or for any other special reasons, such human organ shall not be removed and transplanted without the prior approval of the Authorisation Committee."

This clause has been grossly misused over the years. Patients with organ failure have used the clause to feel instant 'affection' for a stranger who is willing to donate his/her organ for money; later the same person may claim he/she was duped or not paid enough for the organ, and all the affection that was presented to the authorisation committee evaporates. Doctors often feel they need not object when the law provides a clause to help people whose family members refuse to donate, or who do not have a fit or matching donor. For the medical professional, the plight of the recipient may overrule all objections. Doctors have also argued that it is difficult for them to gauge 'true' affection and that this is the responsibility the authorisation committee.

The authorisation committees, when presented with such a case, look at the provisions of the law. They argue that if the recipient and donor pledge affection in front of the committee members, they need not object unless there is a complaint or some gross oversight. They argue that since the doctor sends such cases to the committee, it is the responsibility of the doctor to verify claims of affection.

Given these difficulties, should this clause be used as leniently as is being done at present or should it be tightened? Can we overlook the exploitation in the 'affection' that is obtained by the recipient or the middleman by luring a donor with money?

“MK Mani, chief nephrologist at the Apollo Hospitals in Chennai, writes, in a 1997 article, “The stalwarts of the unrelated live donor programme continue to do as many transplants as they did before the Legislative Assembly of Tamil Nadu adopted the Act. What is more, they do them with the seal of approval from the Authorisation Committee, and are therefore a very satisfied lot. The law, which was meant to prohibit commercial dealings in human organs, now provides protection for those very commercial dealings” (4).

We must also ask what circumstances compel donors to risk their health to donate an organ. Some case studies uncover the fragility of the economically poor communities of the donors. With reference to a study of why people in Tamil Nadu donate their organs, Madhav Goyal and his colleagues write, “Ninety-six percent of participants sold their kidneys to pay off debts. The average amount received was \$1,070. Most of the money received was spent on debts, food, and clothing. Average family income declined by one third after nephrectomy ($P<.001$) and the number of participants living below the poverty line increased. Three fourths of participants were still in debt at the time of the survey. About 86 per cent of participants reported deterioration in their health status after nephrectomy. Seventy-nine percent would not recommend that others sell a kidney” (5).

Ways to limit the organ trade

Organ sale or donation is a manifestation of poverty and desperation. The commerce in kidneys in India is linked to our socioeconomic structure. An alternative is required, which can help to eliminate organ trade and overcome the shortage of organs. It is time to seriously think of ways by which we can promote the cadaver donation programme.

The cadaver donor programme could gain momentum with additions or amendments in the Act such as these (6):

1. A ‘required request’ law that would make it compulsory for hospital staff to ask for organs in the event of brain death.
2. A mandated ‘choice of organ donation’ clause in driving licenses issued in India.

3. Undertaking postmortem examination at the same time as organ retrieval surgery in medicolegal cases. At present, after surgery for organ retrieval, the brain dead person is again subjected to a postmortem; this causes unnecessary emotional trauma to already aggrieved relatives.
4. De-linking hospitals where organs can be retrieved from hospitals where they can actually be transplanted. Moving bodies from a hospital that is not approved to another that is approved limits the number of brain dead patients made available. Such movement is difficult in brain death situations and it's traumatic for the patient's relatives.
5. Making it compulsory to appoint transplant coordinators in the intensive care units of hospitals undertaking cadaver organ transplant, in order to identify and maintain brain dead patients. This transplant coordinator can be a senior nurse or a doctor

It is also necessary to ensure that sub clause 3 of the Transplantation of Human Organs Act is not misused. It may help to promote living transplant by:

1. Strengthening and making the authorisation committee's work more transparent by including NGOs' representatives on the committee to help with pre- and post-authorisation counselling of kidney donors.
2. Providing uniform guidelines to authorisation committees on how to interview donors and recipients.
3. Recording the proceedings of the authorisation committee meetings.
4. Authorising select labs to undertake tissue matching.
5. Exploring possibilities of paired donations where a close relative or partner is fit and able to donate an organ but is not biologically compatible with the potential recipient. This couple can be matched to another couple in a similar situation, so that both the pairs in need of a transplant receive a matched organ.

It is important to set right the ethics of organ donation and transplant. At a time when cutting edge advances in health sciences

relate to organ regeneration, tissue engineering and cloning, the ethics of kidney transplants is a test and will help us in addressing many medical ethical dilemmas in India.

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Deceased-donor kidney transplantation in Iran: trends, barriers and opportunities

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Abstract

Having enjoyed considerable success in kidney transplantation in recent years, Iran has been named the most active country in the Middle East Society for Organ Transplantation region in providing equitable, quick, and intermediary-free access to affordable kidney transplantation for everyone, regardless of gender and economic circumstances. We are, however, of the opinion that the Iranian model can benefit further from improving deceased-donor kidney transplantation, especially after a fatwa (Islamic edict) in the early 1980s lifted many religious and legal barriers. Deceased-donor kidney transplantation in Iran should be bolstered by establishing a transplantation model, increasing government funds, and encouraging participation of the general public in the Iranian Network for Transplant Organ Procurement. We recommend that an intensive media campaign be launched to heighten public awareness; and more transplantation centres be involved in cadaveric transplantation, with streamlined systems of cadaveric donation registration so as to facilitate the process of finding and relating donors with potential recipients.

Although the efficacy of the Iranian model of kidney transplantation has already been established, there is a growing need to discuss the status of cadaveric transplantation and suggest means to improve it. We sought to survey the status of deceased-donor kidney transplantation in Iran with a view to

offering a statistical description and stating possible limitations and opportunities.

In the Iranian model of kidney transplantation, the living non-related donor (LNRD) programme was designed for the expansion of the kidney donor pool, with genetically unrelated but emotionally related friends and altruistically motivated volunteers comprising the highest number of organ donors. Table 1 presents some important characteristics of this model (1).

The Renal Patients Support Charity (RPSC), a non-governmental charity founded in 1978 by patients with end-stage renal disease (ESRD) under the aegis of the government, runs all the stages of kidney transplantation. Patients with ESRD are confirmed officially, by nephrologists, after appropriate examinations and tests. If a patient is suitable for a transplant, the nephrologist refers him/her to the RPSC, which acts as a liaison agency between potential donors and recipients. The altruistic volunteers register with the RPSC and undergo evaluation in the foundation's clinics. Donors are all 18-35 years old; permission for registration from parents or spouses is mandatory. The potential donor should be in good health, and consent is obtained prior to introduction to the potential recipient. The RPSC receives no financial incentives for finding a donor or for referring the recipient and the donor to a transplantation centre. There is no role for an intermediary or agency in this model; the donor and recipient are introduced to each other at the RPSC and agree upon the centre to be referred to. All kidney transplantation centres are university hospitals and are licensed by the government (1, 2). The significance of the programme is highlighted by the fact that more than 50 per cent of the recipients are poor (3) and find in such intervention the difference between life and death.

The Iranian model of kidney transplantation is internationally recognised as the most active model in the Middle East Society for Organ Transplantation (MESOT) region with an annual rate of 25 per million populations (pmp) (2). Thus far, it has not only yielded patient and graft survival rates comparable to those in Western countries (1, 3) but also eliminated waiting lists and middlemen by offering coercion-free interventions on the

basis of equal opportunities regardless of gender and economic circumstances (1).

Trends in cadaveric renal transplantation

By the year 2000, only 84 cadaveric renal transplantations had been performed in Iran (3). In April 2000, the Iranian parliament permitted cadaveric organ donation after brain death. Since then, cadaveric renal transplantation has enjoyed a gradual rise (2). Before the year 2004, less than one per cent of kidney transplantation in Iran came from cadavers, whereas cadaveric transplantation currently accounts for more than 10 per cent of the annual renal transplantation in Iran (1). In the years 2001, 2002, 2003, and 2004, 70, 96, 167, and 207 cadaveric kidney transplantations were performed in Iran, respectively (1, 2).

In Asia, cadaveric renal transplantation comprises 10 per cent of total kidney transplantation (4). About 2,500 to 3,000 cases of renal transplantation are performed in India each year (5), only two per cent of which are provided from deceased donors (6); this ratio in Korea is five per cent (7). In Malaysia, by the year 2005 more than 1,000 kidney transplants, the majority from living related donors, had been performed (8).

Cadaveric renal transplantation in MESOT countries constitutes 15 per cent of total kidney transplantation, giving the region a favourable status in cadaveric transplantation (9). Some MESOT countries such as Turkey (10), Kuwait, and Saudi Arabia have a higher rate of cadaveric renal transplantation than that of Iran, while some others like Lebanon and Pakistan are behind Iran (11). Developed countries boast the highest rates of cadaveric transplantation; the rates of cadaveric kidney donation in the United States, England, Australia, and Spain are 26.5, 25, 23.1, and 49.2 pmp, respectively (11). Spain has the highest cadaveric kidney donation rate in the world with over 99 per cent of all transplants coming from deceased donors (12).

Cadaveric transplantation and religious beliefs

Transplantation has opened a Pandora's box of complicated religious and moral problems. Both Roman Catholics and

Protestants are inclined to give their blessings to organ donation, believing that the prior disposal of body parts will not hamper resurrection. Jewish law, while prohibiting mutilation and delays in the burial of a corpse, makes provisions for overriding this disallowance to save a life. The Islamic Organisation of Medical Sciences paved the way for cadaveric transplantation many years ago by adopting a resolution recognising brain death. The largest religious belief which for a long time remained opposed to the idea of brain death is Shintoism in Japan, rendering this otherwise scientifically advanced country unable to practise cadaveric transplantation of organs until recently when the Japanese parliament was obliged to intervene. Hindu and Vedic scholars accept the concept of brain death (13). The concept of giving is deep-rooted in the Hindu school of thought; accordingly, there seems to be no major religious objection to the act of organ donation (14).

Problems regarding the concept of brain death

The concept of brain death — or more precisely brain stem death — has not failed to create its own share of problems, either. The burden on the medical community vis-à-vis the said issue is two-fold: not only are the professionals required to assure the public at large of the ethics of organ donation following brain stem death but they also have to ensure that the criteria of brain stem death are coherently enunciated and fastidiously enforced (15).

Barriers to cadaveric transplantation in Asian countries

In contrast to developed countries, the undeveloped nations have no organised cadaveric transplantation programme. Utilisation of cadaveric kidneys in Asian countries leaves a great deal to be desired (16), and an overwhelming majority of transplants are performed using living donors, which has given rise to the nefarious practice of selling kidneys for transplantation in some areas (17). In Asian countries, it is difficult to obtain cadaveric kidneys for renal transplantation not just because of a lack of legal recognition of “brain death” but also because of certain socio-cultural beliefs such as concern about being cut up after death, the desire to be buried whole, dislike of the idea of one’s kidneys

being inside another person, a misapprehension about brain death, and the idea of donation being against religious conviction (18). Cadaveric donation is also hindered by a host of beliefs about ghosts, labelled as “feudal superstitions”. People in countries like Hong Kong, Japan, and the Philippines share the same Asian tradition of not parting with their organs after death. In some countries like Malaysia, kidneys can be harvested at death if the owner of the organs has earlier pledged his kidneys for donation prior to death (18). In response to organ shortages, the Chinese medical community has expanded the range of eligible sources to include those condemned to death as criminals (19); as a result, many patients travel to China for kidneys coming from executed convicts. The Japanese organ transplantation law, enacted in 1997, allows organ procurement from brain-dead as well as non-heart-beating cadavers in very restricted conditions (20).

Barriers to cadaveric transplantation in Iran

Despite its vast potential, cadaveric organ donation in Iran is and will remain under-utilised unless the following major barriers are removed: [1] inadequate public awareness (9, 23), [2] attitude of the medical community (21, 23), [3] frequently held misconceptions about Islamic precepts (22), [4] different conceptions of brain death (21), and [5] a sub-standard network for cadaveric transplantation (22). It is also worthy of note that the other MESOT countries are reported to face almost similar problems (9).

We do not subscribe to the notion that religious and legal laws inherently stymie the propagation of cadaveric transplantation in Iran (4, 9, 24), especially after a groundbreaking fatwa (Islamic edict) by the founder of the Islamic Republic in the early 1980s (1, 25) prompted the Iranian parliament to finally lift major legal impediments to cadaveric transplantations in the year 2000 (1). Nor do we believe that a more intensive approach to living non-related renal transplantation would undermine deceased-donor transplantation in Iran (26).

Opportunities for cadaveric transplantation in Iran

Now that there is legislative and religious backing for cadaveric kidney transplantation in Iran, a country with a population in excess of 60 million, cadaveric kidney transplantation can only improve.

Over 15,000 deaths due to road accidents have recently been reported in Iran, with head injury being the most common cause of mortality (66 per cent) among victims mainly aged 40 or less (65 per cent) (27). Al-Attar believes that in Saudi Arabia with 1,800 road accidents per annum, 12 per cent of road-related mortalities could be relied upon as potential donors (28). We cannot utilise the same method to estimate the number of potential donors because of the differences in the pattern of trauma-related brain death; however, the Iranian ministry of health in the year 2005 arrived at an estimate of 500 (29). In addition to brain-dead cadavers, non-heart-beating donors in the wake of accidents of various natures can be regarded as other potential kidney donors (30).

We suggest that, first and foremost, an Iranian transplantation model be established so as to secure the involvement of the Iranian Network for Transplant Organ Procurement (IRANTOP). Through governmental support it is also possible to launch an effective media campaign for heightening public awareness of a wide range of pertinent issues such as the significance of granting informed written consent for cadaveric transplantation. Increasing the number of transplantation centres offering cadaveric transplantation services, ensuring a closer proximity of harvest and transplantation rooms in transplantation centres, developing intensive care techniques (30), identifying brain-death victims in an intensive care setting (21, 24), and elevating the technical knowhow of transplantation surgeons and physicians (31) can surely enhance the status of deceased-donor transplantation in Iran. Matesanz (32) rightly believes that kidney transplantation can be improved if potential cadaveric donors are converted into actual cadaveric donors.

Table 1.
Characteristics of “Iranian model” for
living unrelated donors of kidneys

No coercion
Genuine donors (altruistically or emotionally motivated)
No middlemen
No financial gains for transplant team
No foreign recipients for Iranian donors
No foreign donors for Iranian recipients
Official financial inducements for donors
No waiting list
Equal opportunities for rich and poor alike

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Sex imbalances in kidney transplants in Iran

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Kidney transplantation is generally considered the treatment of choice for end-stage renal patients who require renal replacement therapy (1). Renal transplantation from deceased donors is the most ethical and preferred method of kidney transplantation for treating end-stage renal failure. However, as the method becomes more widely used, a shortage of kidneys for transplant is growing. Since December 23, 1954, when the first kidney transplantation from a living donor was performed in the US between identical twins, this method has become increasingly common as a way to address the gap between demand and supply for kidney transplants worldwide.

Discussions on the sale of organs are overshadowed by reports of coercion and exploitation. It is also argued that organ markets reduce transplantation from cadaveric sources and altruistic donation.

A number of studies from all different countries have reported the existence of a profound sex imbalance among kidney recipients and living donors; men are in the majority among kidney recipients but women constitute the predominant source for living kidney donations, both in industrialised and non-industrialised countries (2-9). At least one author has stated that this is true for the kidney transplantation programme in Iran as well (3).

The reasons behind these disparities remain obscure. Economic and cultural factors may contribute to gender disparity, especially among living unrelated kidney donations (LURD) (4). We looked at sex differences between recipients and living unrelated donors

in what is termed as “the Iran model of kidney transplantation” (1, 5).

All kidney transplants performed from a living unrelated kidney donor from 1992 to 2006 at Baqiyatallah hospital, a university-based kidney transplantation centre and a major transplantation centre in West Asia, were included in the study. We analysed the sex distribution of our LURD donors and recipients.

A total of 2,414 kidney transplants were conducted at our centre. Of these, 2,172 were from a living unrelated donor. The sex of 1,947 (85.4 per cent) of our LURD kidney donors was reliably documented in our data registry: 1,679 (86 per cent) were male and 268 (14 per cent) were female. Of the 2,172 kidney recipients, 1,397 (64.3 per cent) were male and 851 (35.3 per cent) were female.

The term “Iran model of kidney transplantations” refers to a government-controlled and compensated living unrelated kidney donation programme that has been in operation in Iran since 1988. Volunteers who are willing to donate register at the Society for Supporting Dialysis and Transplantation Patients, a liaison agency between potential donors and recipients. They then undergo various evaluations. The donor is paid a reward from government funds and may receive a gift from the recipient as well. Foreigners may not come into this programme, though they may undergo kidney transplantation from a non-Iranian kidney donor (1).

A number of previous studies suggest that kidney allograft from a male donor represents higher survival and lower rejection episodes compared with kidneys donated by females (10, 11). However, studies from different parts of the world document that women constitute the majority of living kidney donors despite the fact that men are more likely to receive a kidney allograft. This imbalance is more prominent in developing countries (4), though developed countries such as Norway (2) Canada (6), USA (7, 8) and Switzerland (9) also have documented female predominance in living kidney donation.

The reason for these discrepancies is not fully explained. It is possible that such disparity among living kidney donors may

reflect coercion, a higher proportion of donations from wives to husbands (compared to from husbands to wives), and a higher priority given to the health of the man for his income-earning role in the family (2, 4, 6). Simmons et al reported that a significant number of potential donors experienced direct or indirect pressure to donate, although this was not communicated to the medical staff (12).

The sex distribution in our kidney transplant recipient population is comparable with other parts of the world and may reflect the higher proportion of males with end-stage renal disease compared to females (4-8). However, in contrast with reports from almost all over the world, we also noticed a different sex distribution among our living kidney donors.

The reason for such a difference is unclear. The unique LURD renal transplantation programme of Iran may provide an explanation. Because of the incentives paid to living unrelated donors by the government (as well as the gift from the recipient), kidney donation may be a more attractive option for men than for women. As the income earners of families, men are more likely to be potential donors for a compensated kidney donation. Moreover, in Iranian culture the man as the family head will not agree to let his wife to donate her kidney for a reward because it is a social taboo. Finally, surgical scars are not acceptable, especially for young girls. Our data may suggest that in Iran there is no coercion of females to donate a kidney to an unrelated recipient.

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Organ transplant and presumed consent: towards an “opting out”

JYOTIKA KAUSHIK

Abstract

This paper examines the “opt out” system of organ donation wherein the State permits removal of tissue and organs posthumously, unless an express objection is made by the person prior to the death. This paper examines the need for “presumed consent” and the jurisprudential arguments in support of it. The social contract theory and the sociological approach based on the principle of “common good” support this system. However, the ethical concerns raised while implementing such a system are debatable. It is for societies to evaluate the situation and make a choice between “ethics” and “common good”. The answer may not be obvious in a country like India where religion may supersede the question of life and death. The paper critically assesses both the issues, and concludes that presumed consent may be a viable method of addressing the organ shortage in India. However, we need public discourse and public awareness to change people’s attitude to this concept.

Introduction

The viability of organ transplantation as a means of saving lives cannot be denied. Organ transplantation has become indispensable for ensuring the survival of many and thousands of people all over the world lose their lives due to severe shortage of organs (1). The official policy underpinning almost all transplant regimes is that of organ donation. Consent assumes a central place in legal and ethical analysis of transplantation practices, notably with regard to living donors but also vis-à-vis cadaveric donors (2). In the latter connection there is an ongoing debate as to whether express

or presumed consent regimes are the preferred legal response, the premise being that the latter will result in a greater volume of organs for transplant.

The availability and use of cadaveric organs and tissue is inevitably closely connected to the ability and willingness of the deceased (prior to death) or surviving relatives to veto removal (3). There are essentially three ideal-typical systems: opt in, opt out and conscription. An "opt in" or "contracting in" system is one permitting tissue and organs to be posthumously removed for transplantation only with appropriate consent.

An "opt out" or "contracting out" system is one permitting tissue and organs to be posthumously removed for transplantation unless an appropriate objection is made. It is argued that the term "presumed consent" is misleading because consent is fictionalised in the absence of any positive indication that permission for posthumous removal for transplantation has actually been given (2). A distinction can be made between systems that recognise objections only from the deceased prior to his death (narrow opt out systems) and those that recognise the objections of the relatives after his death (wide opt out systems). Opt out systems can also differ according to the level of formality required for registering or recording an objection and according the grounds for a valid objection (eg religious conscientious objection only). Most supporters of this system envisage a narrow opt out system in which the objection need only be recorded on a formal register without any reason being required.

A "conscription system" is one where tissue and organs can be removed posthumously for transplantation, irrespective of any consent or refusal. Under such a system, dead bodies and their parts would be treated as public property either indefinitely or for a limited period before what remains is released for burial.

Need for presumed consent

There is dissatisfaction with the current regime of informed consent which has led to progressive deepening of the imbalance between the need for and supply of solid organs for transplantation. The reasons often given for the failure of the above regime are: failure

of potential donors to sign written directives; inability to locate existing donor cards; failure of medical personnel to recover organs based solely on written directives; failure of hospital personnel to approach families to request donation when the decedent does not have a donor card, and the family withholding consent.

In addition to the obvious cost represented by the deaths of patients on the waiting list, there are other significant economic and non-economic costs associated with the shortage of human organs for transplantation. Research has indicated that, compared to dialysis, a successful kidney transplant saves as much as \$60,000 per patient over a five-year period (4). The non-economic costs include reduction in the quality of life with restriction of mobility and inability to work. The enormous hardship suffered by the living donor, the patient on the waiting list, as well as the family of the patient, cannot be discounted.

Conscription is a stronger form of presumed consent and the property rights to the organs of all deceased individuals are transferred to the pool of potential transplant recipients (5). Though this system may increase the availability of organs, the political feasibility of such a regime is doubtful as it is likely to meet with overwhelming objections by the general public (6).

Many countries such as France, Greece, Portugal, Spain, Luxemburg, Austria, Belgium, Denmark, Great Britain, Italy, Norway, Sweden, Turkey, Singapore, Israel, Japan, Switzerland etc have tried to increase organ donation rates by implementing a presumed consent or opt out approach to organ donation. Organ donation rates in Belgium, Spain and Austria suggest that the presumed consent approach may have a positive effect on rates of organ donation. For instance, the number of organ donors in Spain has risen continuously from 14.3 per million population in 1989 to 25 per million in 1994 (7). The most celebrated success of these experiences is the case of Belgium, where organ recovery more than doubled following implementation of its policy of presumed consent (8).

The laws in these countries may vary (9). For instance, the French and the Belgian systems of presumed consent permit the removal

of organs from the cadavers of persons who have not, during their lifetime, indicated their refusal to permit such a procedure, with exceptions for the cadavers of minors and the incompetent. Both these countries allow due regard to the wishes of the next of kin. The Austrian model differs in that it is not hindered by deference to the wishes of the next of kin. As a result, Austria has had much more success in procuring organs, supplying kidneys twice as effectively as the United States and most European countries (10). Brazil's experiment with presumed consent illustrates the drawbacks of the presumed consent model. The Brazilian law moved from a voluntary donation system to a wide opt out system, which had to be abandoned due to lack of awareness among people, hesitation of doctors in removing organs without the consent of the family, and certain administrative difficulties (11).

An opt out system requires that the deceased and his surviving loved ones have little moral claim to control what happens to the cadaveric material, or that any such moral claims are attenuated by positive duties owed to those in need of cadaveric material (3). A presumed consent system is not only effective for procurement of organs for medical purposes, but can also be an effective way of controlling the black market by addressing the acute shortage of organs. In addition, presumed consent leads to improvements in tissue matching between donor organs and recipients, and it allows surgeons to be more particular about which organs are selected.

Jurisprudential justifications

The social contract theory actually justifies non-consensual body part appropriation by the State (12). Rousseau, Rawls, Hobbes and Locke carved out early thinking on social obligations, duties and responsibilities for the nation state. According to Rousseau, "Through our relationships with the State are born obligations that are entered into involuntarily for the good of the common or the whole." (13) He refers to these as general wills, in which the best interest of the group is common or the whole. Presumed consent, as with other organ procurement schemes, poses ethical and legal challenges. Fentiman, Dukeminier and Nelson argue that these moral challenges are largely overcome by the tremendous social good that is done (13). Proponents suggest that presumed consent

could ease the collective suffering and death of people awaiting organ transplants. Accordingly, they also argue that the policy maximises a community good for the benefit of all people, with a relatively small collective burden (13). It has been held by the American courts that “the State has to rely on social contract to address public health concerns and a fundamental principle of the social contract requires that citizens are governed according to common good, and therefore must sacrifice, comply and otherwise acquiesce to that ‘common good’.” (14)

Rawls’s conception of the “original position” and his theory of distributive justice include the equitable distribution of primary goods in a manner that is for the greatest benefit of the least advantaged (13). Though it assumes a definite limit on the strength of social and altruistic motivations, it relies on the theory that the decisions taken will be for promoting common good. Thus, adopting the system of presumed consent can effectively combat organ shortage in the interests of the general public.

Roscoe Pound postulates that “law as a form of social control needs to be adequately employed for enabling just claims and desires to be satisfied, must be developed in relation to existing social needs.” (13) An organ donation law based on a system of presumed consent which leads to an increase in the availability of organs then may also be justified as being in the social interest.

Criticisms

However, this system had been criticised on various grounds. It has been argued that presumed consent disregards autonomy, privacy and the right to choose how one’s body will be used after one’s death. Contrary to this it is argued that presumed consent respects the principle of individual choice by giving objectors to organ donation an opportunity to empower their anti-donation preference and thus does not infringe the right to choose. It is argued that an individual’s interest in preserving bodily integrity while alive is not equivalent to bodily integrity after death and the former gains precedence over the latter (15).

Another criticism that is levelled is that a social contract, along with any legal transaction, should be granted legitimacy only

according to its potential for equitable implementation and results (3). Presumed consent has been criticised on the grounds that it may lead to exploitation of the vulnerable sections of society and there may not be an equitable allocation of organs (16). Also, certain cultural expectations and religious doctrines emphasise human dignity, the sacredness of the body, and preservation of life, even when medically the body is considered to be “dead”. However, the main reason why the “opt out” system is preferred to the “conscription” system is that it gives the individual the autonomy to withdraw her consent based on the above or any other considerations.

Presumed consent laws have also been criticised for assuming that organs and tissues belong to the State or to society rather than to individuals or families. However, such criticism does not necessarily hold, for such laws could be held to be presuming donation rather than assuming communal ownership of the bodies. Also, the question may arise whether it vests the property interest in the body to the State. Answering the above criticism it was held in the case of *Brotherton v. Cleveland* that “Under the Anglo-American Common Law there is no property right in the cadaver, instead the next of kin in the United States have a quasi property interest in the body which is limited to custody of body for burial or lawful disposition.” (17). In his discourse on property, Locke defends the right to physical subsistence even when it undermines property rights (18). Presumed consent cases do not address whether a property interest was at stake or not. They focus instead on the value provided to the greater society balanced by an abrogation of the rights of the deceased or her kin. It is argued by the proponents of this system that if a property right is abrogated by the State’s interest in preserving the health of the living, then this would be properly within the scope of the State’s authority, pointing to a social contract between the State and its citizens (12).

Public awareness

The “tacit consent” appealed to by John Locke is a consent that is expressed silently or passively by omissions or by failures to express or signify dissent (12). The system of presumed consent

envisioning a similar tacit consent but also stresses providing all the relevant information to the potential consenters. The potential consenters must be aware of what is going on and must know that consent or refusal is appropriate and must have a reasonable period of time for objection. They must understand the expected means of performing dissent and these means must be reasonably easy to perform. Finally, the effect of dissent must not be extremely detrimental to the potential consenter (19).

Fuller stresses that the publication of law is the most important duty to fulfil the inner morality of law (13). In the case of presumed consent laws this becomes all the more important since there may be a large body of people against it. Also, in order to ensure that people always have a choice to "opt out" if they so please, it is critical that there is widespread dissemination on the means by which they may express their objection. It has been observed that public attitudes tend to be an impediment to organ procurement. Media publicity, highly visible public and parliamentary debates, public education and hearings are necessary for the promotion of such laws (13). Habermas's theory of "social construction of reality" emphasises the need for "use of the public sphere" and discourse as an essential ingredient of law (20).

According to Hart's conception of obligations, the regulation of self and society requires not just legal instruments; it also requires that individuals and groups internalise the public moral norms as part of their own internal value systems. These norms inform the choices that they make for themselves and their society to ensure that all people have the capability to be healthy (13). Such internalisation in turn leads to the greater efficacy of, and greater compliance with, domestic policy and legal instruments. It is submitted that promoting laws through the above mentioned means may actually help change the attitude of people to organ donation, and the introduction of a presumed consent law may help people internalise the values associated with it.

Conclusion

As the above discussions show, criticisms leveled against presumed consent may be circumvented for the benefit of society.

Though presumed consent laws may alleviate organ shortages, it is important to understand how societies may perceive and respond to legislative changes of this nature. It is also necessary to have an effective organ procurement system with adequate safeguards to protect the interests of individual citizens from potential abuses inherent in gaining presumed consent for organ donation.

Currently there are two types of presumed consent removal statutes in the United States: quasi, which require a search for the next of kin to obtain consent, if the search is successful; and pure, which requires no search or consent of the family (21). Both types of presumed consent statutes are typically limited to the removal of corneas and pituitary glands. The courts in these states have upheld these presumed consent legislations (22).

Considering that the system results in higher rates of organ procurement it may also be beneficial to introduce presumed consent legislation in India. However, this will be possible only after creating widespread awareness about organ transplantation and addressing the religious and cultural overtones that are associated with it. It can be effective only when there is good infrastructure, for instance an actively involved government agency that coordinates procedures for the removal, distribution, transportation and transplantation of organs.

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Presumed consent: a problematic concept

AAMIR M JAFAREY, FARHAT MOAZAM

In her article, Jyotika Kaushik addresses an important issue, that of the increasing shortage of kidneys available for transplantation worldwide (1). As a solution for India, Kaushik favours the introduction of the “presumed consent” system to allow retrieval of organs from recently deceased persons. In this system, unless an individual has specifically expressed, in writing, during her/his lifetime, that he/she is unwilling to donate an organ following death, his/her organs can be routinely harvested by healthcare professionals for transplantation into others. In our commentary we examine some of the arguments put forward by the author in support of presumed consent, and discuss ethical, professional and social problems connected to the use of this system as a way to address the scarcity of transplantable organs. However, we will begin by first highlighting what we consider to be a critical factual error in the article.

The author states that it is “dissatisfaction with the current regime of informed consent” that has “led to progressive deepening of the imbalance between the need for, and supply of, solid organs for transplantation”. In reality, the widening gap between the supply and the demand for organs is a far more complex issue, and it has occurred despite a steady global rise in the numbers of living and deceased donations. Technological advances, sophisticated surgical skills, and progressive improvement in immunosuppressive regimens have enlarged the pool of individuals who are now accepted as “transplantable”. Patients not considered suitable candidates for kidney transplantation only a few years ago -- infants and children, the very old, those with co-morbid factors such as diabetes, patients with more than

one previously failed kidney transplantation -- are now routinely offered this procedure.

In addition, the gap between the number of kidneys available for transplantation and the number of patients waiting for a transplant is widening for a number of reasons. These include longer life spans leading to age-related illnesses, obesity and a concomitant increase in the incidence of diabetes worldwide, and the failure to focus on prevention of renal diseases, all of which are also contributing to greater numbers of people developing end-stage renal disease. Without appropriate attention to some of these factors, no measures can ever be successful in providing sufficient kidneys to meet the rising need (2, 3).

Is it really “consent”?

The term “presumed” consent is ethically problematic. As defined, it is in direct opposition to the moral premise on which “consent” rests within healthcare delivery systems. It also negates the ethical basis of the relationship between healthcare providers and the public. Taking and giving consent to donate an organ, whether during an individual’s lifetime or to occur following his/her death, is an ethical process; it involves a dialogue in which all relevant information is provided to the potential donor, complete comprehension is ensured, and this is followed by an un-coerced decision by the individual to either donate an organ or refuse to do so.

To therefore “presume” by default that we have “consent” to remove organs from a deceased person, because there is no prior statement from him/her against such an action, cannot be said to meet the universal criteria for ethical consent as understood by the medical profession. A “presumed consent” would be analogous to the practice of taking the silence of a young woman as her consent to marry a 75-year-old groom. This term can be argued, with some justification, to be an example of an oxymoron along the lines of “honour killing” or “jumbo shrimp”.

Negative impact on the profession

Transplanting an organ is undertaken by a team of healthcare professionals and can be among the most lucrative procedures for physicians and staff of a hospital. Legal sanction allowing physicians to routinely remove organs from those who die in hospital without a pre-mortem statement forbidding this can have profound negative repercussions on the medical profession and on a physician's relationship with patients and family members. It is not far-fetched to imagine growing public suspicion that physicians, instead of doing everything they can to save the lives of the critically ill, are more interested in obtaining as many kidneys as they can following death.

Such perceptions would be far more pronounced among the poor and the powerless in society. This fact has also been documented in African American communities in the USA and is reflected in their attitude to organ donation (4). It should be noted that while the dominant western physician-patient paradigm is of a "contractual" relationship between "equals", the hierarchical systems and power differentials that exist in South Asian societies define the same relationship as primarily a fiduciary relationship in which trust/faith (*bharosa* in Urdu, *vishwas* in Hindi) between the two parties is central. In a system of presumed consent for routine removal of organs, this trust between patients and healthcare providers would be the first casualty, with far-reaching consequences for healthcare providers and their relationship with society.

The patient, the family, and the physician

The centrality of the family in major human life events - birth, illness and death - is a universal phenomenon even though the level of family involvement may vary from one society to another. In most Asian societies, major decisions are taken collectively by members of the family (5). Presumed consent, on the other hand, is based on an individual's right to prohibit harvesting his/her organs following death and the right of the physician to proceed to do so in the absence of this prohibition. The family plays no role in this decision-making dyad. But abstract "text" or law is different from the living "context" of a situation. Physicians faced

with distraught, grieving families opposed to removal of organs from a recently deceased son or daughter will find it impossible to counteract their wishes. The inadvisability of doing so on moral and compassionate grounds, and fear of the negative impact on the image of the physician involved, would outweigh the legal cover for the act. In countries such as the USA, even when a deceased has given prior written permission via a donor card to donate organs following death (called the "opt in" system in contrast to the "opt out" or presumed consent system), physicians do not harvest the organs if there is opposition from the family.

Kaushik herself acknowledges the importance of family sentiments when discussing presumed consent systems in European countries, including Spain, which has one of the most successful deceased donor programmes in the world. The success of the Spanish programme is largely due to substantial financial and manpower investment in intensive ongoing public education and engagement. As a result of this, the number of families who oppose deceased donation has decreased dramatically. Nevertheless, as Kaushik notes, the family of the deceased is allowed the last say if found unwilling to allow organ harvesting. To do otherwise would jeopardise public goodwill and trust without which no organ donation programme of any kind can ever succeed.

Kaushik argues that a legal statement prohibiting use of one's organs following death would help to "empower" the individual, but this is an individualistic view which may not hold true within the collective realities of societies such as ours. The average citizen in countries with high illiteracy rates seldom makes an elaborate will indicating distribution of possessions following death. Death is not considered a suitable topic for discussion, and it is taken for granted that the family knows best and will take care of the formalities. In this cultural milieu, it is unlikely that an individual will be interested or motivated enough to draw up a document indicating the manner in which his/her organs should be dealt with; it is even less likely that this will be regarded as an act of empowerment.

Organs as “goods”

The death of a member of a family is not perceived merely as a medical or legal event by the bereaved family, but one that is imbued with emotional, psychological, and religiously symbolic meaning. The process of mourning and coming to grips with the loss of a loved one involves customs and religious practices that are intimately connected with how the body of the deceased must be dealt with (6). These are all the more pronounced in traditional family-centred societies. The system of presumed consent, on the other hand, rests on a philosophical, legal premise that following death, organs are “goods” that can be used for the benefit of society, reducing them to objects of utility not too different from shoes and clothes left behind by the deceased.

Kaushik employs the argument of a “social contract” and positive duties owed to others in society to support a system of presumed consent, but worries that family resistance can jeopardise obtaining organs from the deceased. Logically, it seems to us that her arguments about a social contract and the duty to address the needs of society are more in tune with employing the conscription model as a solution to kidney shortages. This model does not require the involvement of the individual or family at any point and allows organs to be routinely removed from the deceased for transplantation into others. The author does not advocate conscription as a mode of organ procurement because she is concerned about the potential negative effect on public perceptions. But in our opinion, this concern is equally valid for a system of presumed consent which, in societies such as India’s, is liable to end up with the body parts of the least-advantaged being harvested for the benefit of the most affluent.

Where we agree

Having said this, we are in complete agreement with the author when she stresses the need for greater awareness and education of the general public about the need for increasing organ donation, both from the living and the deceased. To increase the latter in countries such as ours, we believe we must aim for efficient “opt in” models in which increasing numbers of citizens, in consultation

with their families, register their informed, voluntary, consent for donation of organs following death. Kaushik is also correct in pointing out the importance of sound infrastructures to develop successful deceased donor programmes.

To make all this happen requires collective efforts by the medical and legal professions, the media, members of civil society and the government. Without initiating concrete steps and continuing hard work, it is highly unlikely that we can reduce the deficit of organs. In fact, attempts to legally enforce presumed consent, or any other system for that matter, before preparing the ground, could alienate the public, erode their trust in the medical profession, and impact the organ transplantation endeavour in profoundly negative ways.

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Will presumed consent make transplantation accessible, ethical and affordable in India?

SANJAY NAGRAL

Organ transplantation is now a well established life saving procedure for patients suffering from end-stage disease of various organs. In the last four decades, the concept of “brain death”, a state where the brain is irreversibly damaged but the heart is beating, has been legalised and accepted in many countries of the world. A majority of transplants are now done with organs retrieved from such brain dead individuals. The need for organs, however, far outweighs their availability and a large number of patients still die waiting for organs.

The form and method of obtaining consent for removal of organs from brain dead individuals has evolved over the years. Generally, two forms of consent are practised. The most common is “informed consent” in which close family members agree to donate organs after brain death has been certified. Often, this means that the treating doctor or a trained counsellor has to communicate with the family and motivate them to agree to organ donation after brain death has been declared. Medical professionals may be reluctant to do so for fear of inviting the wrath of family members in an emotionally charged situation. Besides the trauma of losing a close family member, various cultural, religious and social beliefs may prevent the family from giving such consent. Even in countries with a long history of such organ donation, consent rates have rarely exceeded 50-60% and have plateaued in the last few years.

In order to improve the donation rate, other strategies have been proposed and implemented. In many countries “donor cards” are provided which citizens sign and keep during their lifetime. This

makes it easier for family members to take a decision. Some states of the US have what is termed a "required request" which makes it mandatory for the doctor to ask the relatives of a brain dead patient about organ donation. In some European countries such as Austria, Belgium, Denmark, Finland and France, "presumed consent" has now been legalised and is practised. This grants authority to doctors to remove organs from brain dead individuals whenever usable organs are available, in the absence of any objection from the deceased in his or her lifetime, or from family members. Presumed consent places the burden of opting out of organ donation on those who object to this procedure. This form of consent was introduced in these countries after a long history of cadaveric donation as well as public debate on the issue. It must be noted, however, that in spite of such measures, the discrepancy between demand and supply of organs continues to grow.

When the Human Organs Transplant Act was passed by the Indian Parliament in 1994, it had a dual purpose. Besides banning trading in organs, it legalised brain death, making removal of organs from persons declared brain dead permissible after obtaining the consent of the family. The 15 years since the passage of the law have seen negligible activity in cadaveric donation. In many states it has been as good as a non-starter. Even in cities such as Chennai and Mumbai, where there has been some activity, it has not been consistent. It is against this background that attempts are being made to modify the law both to ease the procedure of organ donation and to offer "legitimate" incentives to donor families. States like Tamil Nadu have recently issued directives which put pressure on medical institutions to identify and approach families of brain dead patients. Such measures have seen a marginal rise in donation rates.

Kaushik's paper in this issue gives a well structured historical, judicial, philosophical and social perspective on the need for, and evolution of, the idea of presumed consent (1). It is comprehensive in the ground that it covers and relevant in a country where organ donation has failed to take off 15 years after it was legalised. As a surgeon involved in organ transplantation and hence regularly seeing patients dying while on the waiting list for cadaver donation,

I am tempted to support her call for considering the introduction of presumed consent in India.

However, any observer of the social as well as healthcare scenario in contemporary India will inevitably have to first question the relevance of the debate over consent in a country that denies basic healthcare to a large section of society (of course this argument can be extended to the entire field of organ transplantation which is presently beyond the reach of most people). Even if one decides to look at it purely from the viewpoint of those dying while waiting for transplants, societal acceptance of constructs that have their origin in a developed western Anglo Saxon society needs discussion. And, finally, one shudders to think of the Pandora's Box that such legislation would open in a country that has a completely unregulated healthcare system and vast class, caste and regional imbalances.

To be fair, though Kaushik's article largely restricts itself to the US and Europe, where the presumed consent concept has been developed and implemented in various forms, it informs us that a similar experiment in Brazil did not work. It is silent on Asia and the rest of South America (where organ transplantation is common in many countries and which is culturally closer to India) where such a proposal has not been introduced. Kaushik also alludes to the problem of implementation when she says: "It can be effective only when there is a good infrastructure, for instance an actively involved government agency that coordinates procedures for the removal, distribution, transportation, and transplantation of organs."

The argument of "the greater common good" is indeed a complex and interesting one. At a broader sociological level it throws up many questions beginning with the terminology itself. For example, who constitutes the "greater common"? And how does one decide what is "good"? In the context of healthcare in general, can we use the common good argument to, for example, legislate to stop people in large cities using automobiles and instead use public transport to reduce pollution, which is a major silent killer? Or should we ban smoking and alcohol completely

as they not only cause disease but also are health risks for society in general?

After arguing for the implementation of presumed consent, Kaushik admits that “this will be possible only after creating widespread awareness about organ transplantation in the country and addressing the religious and cultural overtones that are associated with it”. The history of the last 15 years in India shows that we are far from creating any such awareness. Most large institutions have failed to even set up a basic mechanism for approaching families of brain dead individuals. The lack of progress in cadaver donation is often ascribed to lack of public awareness, but this is not entirely true. In the hospital in Mumbai where I work, a concerted effort was made to increase donations with the appointment of a dedicated transplant co-ordinator and education of staff. As a result, the consent rate is around 50%, which is close to that of western countries. Recent experiences of armed forces’ medical institutions and some institutions in Chennai are similar. It seems that if institutions make efforts to promote organ donation and identification of brain dead donors by ICU personnel, the consent rate is likely to be good. Cadaveric transplants are not being performed not because of lack of awareness and refusal by families to donate, but because of absence of institutional mechanisms to approach families of brain dead individuals. It is the same story as in eye and blood donation which has a much longer history in India. Perhaps this reflects the state of healthcare in India where activities like organ donation suffer because government institutions are grappling with basic problems, and private institutions do not see it translating into profits.

Even in its present limited form, cadaveric donation in India largely benefits the rich. Also, given the cost, transplantation is at present offered to a miniscule minority of patients suffering from end stage disease of organs. In the context of presumed consent, where all sections of society will be involved, it is difficult to see how, in an already lopsided system, one ensures equitable distribution of organs based on those who need it rather than

those who can afford it. And do we have the ability to monitor the implementation of such a system in the completely unregulated market of healthcare and protect it from potential abuse? Thus, whilst trying to achieve an increase in organ availability by such a drastic leap, are the proponents of this system willing to go beyond availability and simultaneously look at making transplantation accessible, equitable and ethical?

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Issues related to non-heart-beating organ donation

RAJESH BARDALE

Abstract

Since the enactment of the Transplantation of Human Organs Act, 1994, the brain dead person remains the primary source of organs legally obtained for transplantation purposes in India. With the increasing demand for organs for transplantation purposes, non-heart-beating donors can help meet this need. However, the process of retrieving organs in non-heart-beating donors is more complex, and raises ethical and legal as well as medical issues. This essay discusses some of these concerns.

Since the enactment of the Transplantation of Human Organs Act, 1994, the brain dead person remains the primary source of organs legally obtained for transplantation purposes in India. However, the demand for organs has always been high and continues to grow, and potential donors are few, so the supply of organs remains limited. Therefore, alternative sources have been sought, including the retrieval of organs from individuals declared dead according to cardiopulmonary criteria, that is when cardiac function ceases. Such individuals are known as non-heart-beating donors (NHBD) (1).

The NHBD is defined as one who sustains cardiorespiratory arrest and whose organs are retrieved after irreversible cessation of cardiac and respiratory function (2). In contrast, a conventional heart-beating donor is one who sustains irreversible brain insult and whose death is based on neurological criteria. The concept of NHBD is not new. When organ transplant programmes first started, all organs were retrieved from patients immediately after

cardiorespiratory arrest (3). However, with the recognition of brain death, the use of NHBD has decreased considerably.

The modified Maastricht classification of NHBD identified five categories of potential donors. A more practical classification may be “uncontrolled” or “controlled” NHBD depending on whether cardiopulmonary function ceases spontaneously or after medical therapy is withdrawn. Donors from categories 1, 2 and 5 have been classified as uncontrolled donors whereas those in categories 3 and 4 are described as controlled donors (3).

The modified Maastricht classification of non-heart beating donors	
Category	Type of potential donors
I	Dead on arrival
II	Unsuccessful resuscitation
III	Awaiting cardiac arrest
IV	Cardiac arrest in a brainstem dead donor
V	Unexpected cardiac arrest in a critically ill patient

It is proposed that NHBD could contribute to an increase in the number of solid organ and tissue donation for transplantation purposes. The solid organs that are suitable for transplantation purposes include the kidneys, liver, lungs and pancreas, and tissues such as corneas, bone marrow and pancreatic islet cells (1, 3, 5, 6). The results of transplantation of kidneys are encouraging (7, 8) and the recipients of NHBD kidneys have a five-year survival that is the same as those who receive a conventional heart-beating donor kidney (2). It is estimated that the introduction of an NHBD programme would have the greatest impact on the cadaveric organ pool compared to cadaveric donations (9). However, the retrieval of organs for transplantation is more complex in NHBD due to time constraints, medical concerns about organ damage owing to “warm ischaemia”¹ and the ethical and legal issues involved therein.

Ethical issues

The procedure of retrieval organs in NHBD raises ethical concerns and these issues deserve attention. In these donors, to

minimise the organ damage due to warm ischaemia, some centres use postmortem *in situ* preservation. There are data showing that *in situ* preservation can lengthen the permissible period between the determination of death and organ retrieval from one hour up to six hours (1). Similarly postmortem interventions such as putting the dead on ventilation and cardiopulmonary bypass are done in an attempt to preserve the organs. At times, these procedures are done without the knowledge and consent of family members. The intention of these procedures is to prevent warm ischaemia and organ damage, but they raise ethical concerns. Conducting an invasive procedure without the consent of the patient or relatives or, alternatively, failing to act in the patient's best interest, amounts to assault. It might be argued that it is unclear whether interference with a corpse without legitimate authority would be considered a crime, there being no property in a body. However, the act can be construed as indignity if done with intention (section 297 of the Indian Penal Code, IPC). Similarly the deceased's relative may file a claim for mental trauma, particularly if the interference has been witnessed (10).

The use of controlled donors allows organ retrieval to be planned, warm ischaemic time to be minimised and the usage of organs for transplant optimised(3). But ascertaining death is important. Questions are often raised regarding the certification of death. The NHBD protocol rests upon the "dead donor rule": patients must be dead - according to a specified definition - before organ retrieval, and death must be neither caused nor hastened by retrieval (11). To declare a person dead by cardiopulmonary criteria, it must be established that circulation and respiration have ceased and their function will not resume. However, these functions may reverse spontaneously (autoresuscitation) if they were due to a disturbance of the cardiac rhythm, or they may be reversed by interventional resuscitation (10). Menikoff (12) has criticised the definition of death in NHBD programmes, noting that the cessation of cardiopulmonary activity is not irreversible as long as there is a possibility of its being restored by resuscitation. Supporters of NHBD argue that if a specified duration of absent cardiac activity is not associated with spontaneous autoresuscitation, then the absence of activity

can be considered irreversible (1). The Maastricht workshop considered that 10 minutes without perfusion² of the brain was necessary before any intervention geared towards organ retrieval. The Institute of Medicine recommends a five-minute observation period. The Pittsburgh protocol sanctions surgical retrieval of organs at two minutes after asystole³ (10). Despite the premise of certainty in determining irreversible death, it is worrisome that centres cannot agree to adopt a common standard (1).

Second, concerns are raised about the methods used to decrease warm ischaemic time. NHBD protocols commonly use heparin to prevent intravascular clotting and pentolamine to maintain vascular perfusion. These agents are given when the patients are alive. Neither of these medications can be considered for use for the benefit of the patient. As such, would their use not seem to violate the ethical responsibility to the still alive patient?

The practice of cannulation of the patient, prior to withdrawal of care, for the purpose of preservative perfusion is also not acceptable. It could be argued that interventions of this nature would require an escalation of analgesic and sedative or anaesthetic agents with the potential for destabilisation of the cardiovascular system, thereby precipitating, or priming for, a more rapid death. The process too could not be contained within the principle of "double effect". That principle holds that an action that produces a good effect and a bad effect might be permissible if the good effect is intended and the bad effect is merely foreseen but unintended. Cannulation might have been permissible for giving medicines; here it is done to preserve the organs by injecting a preservative perfusion. It does not benefit the patient, so any foreseen and harmful effect not ethically permissible.

Another question is related to the withdrawal of active treatment. In the United Kingdom, the decision to withdraw treatment is made in accordance with the guidelines of the Intensive Care Society, the British Medical Association and the General Medical Council. In the Indian context, explicit withdrawal of active treatment is a relatively new phenomenon. No national guidelines are available and there is a lack of education in bioethics and a paucity of case

law in India (13) on this subject. While applying these programmes in India, uniform national guidelines are needed. Moreover, it is important that withdrawal of active treatment should be according to a protocol and should not differ when organ donation is being considered. While taking such decisions, the benefit of the patient should be paramount. There must be an absolute prohibition on active euthanasia. Similarly, if the withdrawal of active treatment is being considered for harvesting organs, it should be mandatory that the transplant team is not involved in any decision to withdraw treatment. This ensures that the interest of the dying patient remains paramount. The decision to withdraw treatment should be communicated to the family by the clinician and should be documented in the clinical notes.

Medicolegal issues

In India, the Transplantation of Human Organs Act, 1994, provides for the regulation of removal, storage and transplantation of human organs for therapeutic purposes, and for the prevention of commercial dealings in human organs. It gives legal sanction to cadaveric organ donation. According to this Act, a deceased person means a person in whom permanent disappearance of all evidence of life occurs, by reason of brain-stem death or in a cardiopulmonary sense, at any time after live birth has taken place (14). According to section 3 (3) of the Act, in the absence of a living will, the person in lawful possession of the body may make the decision to donate the organs. The medical team should use only those organs for which consent has been given, and the remaining tissues and organs should be treated with respect (15).

Medicolegal cases are a valuable source for organ retrieval for transplantation purposes. However, section 4 (1) of the Act restricts the retrieval of organs. According to this section,

...removal of organs [is] not to be authorized, if the person required to grant such facilities, or empowered to give such authority, has reason to believe that an inquest may be required to be held in relation to such body in pursuance of the provisions of any law for the time being in force.

Therefore, without proper authority, the removal of organs before or at autopsy may attract action amounting to causing indignity to a human corpse under section 297 of the IPC against the doctors involved in the organ retrieval, or the autopsy surgeon. After the death of a person, in medicolegal cases, the body is handed over to the police for further formalities and investigation. The police take possession of the dead body. When a body is in police custody, no intervention of any kind can be done on the dead body without obtaining proper written consent, permission, or a no objection certificate from the police. Any intervention without permission may amount to destruction of evidence or “disappearance of evidence” as mentioned under sections 201 and 202 of the IPC.

It is also stated in section 6 of the Act that in cases where the body has to be sent for medico-legal autopsy, a person deemed competent under this Act may authorise the removal of certain organs from the body if he or she has reason to believe that such organs would not be required for the purpose for which the autopsy was being conducted, provided that he is satisfied that the deceased person has not expressed an objection to any of his organs being used for therapeutic purposes after death. The competent authority under this Act is not clearly defined. The authority seems to have been vested in the autopsy surgeon who is in lawful possession of the dead body for postmortem examination (16).

The All India Institute of Medical Sciences, New Delhi, has framed guidelines to carry out the retrieval of organs in medicolegal cases without violating any of the procedures prescribed under the law. The advantage of these guidelines is that the procedure does not hamper the functioning of the investigating officer, the autopsy surgeon or the courts of law (16). However, these guidelines are formed for organ retrieval in brain-stem death cases. Similar, uniform guidelines are needed for an NHBD programme. The presence of such guidelines will help retrieve organs from medicolegal cases after observing legal procedures and without violating existing laws.

Conclusion

In conclusion, it can be stated that non-heart-beating donors can, to some extent, help meet the increasing demand for organs for transplantation purposes. In order to implement such a programme in India, a comprehensive discussion should be had to address the ethical, medical and legal issues involved therein and arrive at a clear policy. An NHBD programme should be implemented on a need basis and not on a demand and supply basis; in the medical field, especially when organs are being retrieved, the programme should be implemented for the benefit of the patient according to need and priority.

Notes:

- ¹ The organ when removed from the donor is ischemic (has poor blood supply) till it is put into the recipients body and hooked up to blood vessels. The period during which it is exposed to room temperature is the 'warm ischemia' period. If this period is long the organ gets damaged.
- ² Perfusion is adequate blood supply.
- ³ When the heart ceases to beat

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Are we ready for non-heart-beating organ donation in India?

SANJAY NAGRAL

With the success of organ transplantation as an effective modality of treating end stage disease of various organs, increasing numbers of organ transplants are being performed all over the world. However, this procedure requires a donor pool of either living or cadaveric donors. Since this pool is limited, the gap between demand and supply is widening. In the context of organ donation "cadaveric" donation has largely meant brain dead or "heart beating" donors. In the last four decades, the concept of brain death - a state in which the brain is irreversibly damaged but the heart is beating - has been legalised and accepted in many countries of the world. However, in spite of the legal sanction as well as sustained campaigning, the number of such donors is limited.

In an effort to increase the donor pool, other strategies are now being implemented. The first area involved improving the consent rate for brain dead donors. This includes "donor cards" which citizens sign and keep during their lifetimes; "required request" where it is mandatory for a doctor to ask the relatives of a brain dead patient about organ donation, and, in some countries, "presumed consent" which grants authority to doctors to remove organs from brain dead individuals whenever usable organs are available, in the absence of objection from the deceased in his or her lifetime, or the family members. The ethical and social dimensions of presumed consent have recently been discussed in the pages of this journal (1, 2).

In this issue Bardale (3) discusses the relevance of a different type of cadaveric donor, the "non heart beating donor" (NHBD), otherwise called "donation after cardiac death" (DCD). As opposed to the brain dead donor, whose brain is irreversibly damaged but

whose heart is beating and hence circulation is intact, these are donors whose heart has ceased to beat and hence circulation has ceased. It is obvious therefore that in this group of donors the organs need to be removed instantly for the organs to be viable for the purpose of transplantation.

It is interesting to note that historically some of the earliest attempts at solid organ transplantation were made from such donors. The first human kidney, liver and heart transplants, in 1958, 1963 and 1967, respectively, were performed using organs from non heart beating donors as at that time the declaration of death required heartbeat cessation. However, since techniques to keep the organs viable were not developed at that time, the results of these early transplants were poor, largely due to ischaemic damage to the organs. With legislation recognising brain death being adopted in many countries, the focus then shifted to using organs from brain dead or heart beating cadavers wherein the procedure to remove organs became a controlled one with much higher rates of success.

In the mid 1990s there was a resurgence of interest in using organs from NHBDs. Institutions in the US reported the use of these donors for kidney and liver transplants with good results (4). Soon this form of organ procurement gained increasing acceptance, and in 1995 the Maastricht classification of NHBDs was put forward (5).

Over the last decade this form of organ donation has slowly gained wider acceptance. However, with its wider application, it has brought up a large number of complex ethical dilemmas. Bardale covers the various ethical and legal issues thrown up in this field. Although many of them are briefly mentioned, it would be obvious to the reader that these are sensitive and complicated areas dealing essentially with the end of life. Therefore the implementation of such programmes in a scenario such as India's will need on one hand social and cultural acceptance and on the other substantive regulatory mechanisms. Also it needs the presence of trained medical teams who can conduct almost instantaneous removal of organs in a planned manner.

When the Human Organs Transplant Act was passed by the Indian Parliament in 1994, it had a dual purpose. Besides banning the

trade in organs, it legalised brain death, making the removal of organs from brain dead cadavers permissible after consent from the family. The last 15 years after the passage of the law have seen some sporadic activity in cadaveric donation. What has been heartening, however, is the response of potential donor families. In the hospital in Mumbai where I work, the consent rate is around 40 to 50%. This is on par with developed countries. The recent experiences of armed forces medical institutions, and institutions in Chennai, are similar. It seems that if an institution makes an effort to promote organ donation, and if ICU personnel make an effort to identify brain dead donors, the consent rate amongst the Indian population is good.

There is no reason to believe that families who consent to organ donation after brain death will not do so after cardiac arrest. In fact it is easier to understand and accept the concept of cardiac death. As a surgeon involved in cadaveric organ donation and liver transplantation, and hence regularly seeing patients dying on the waiting list, it is indeed tempting to consider starting an NHBD programme. The scientific and legal base for it has been prepared in the rest of the world.

However, as Bardale points out, this field is a quagmire of complex moral, social, ethical and legal issues. The critical question therefore is: are we ready for it in India?

Two issues flagged in the discussion on presumed consent bear repetition; do we have the ability to monitor the implementation of such a system in a completely unregulated market of healthcare? And, whilst trying to achieve an increase in organ availability, are we also looking at making transplantation more accessible and equitable?

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Living unrelated kidney donors: ethical aspects of living kidney donation in Brazil

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Abstract

Brazil has established the largest public kidney transplantation system in the world. 46.2% of transplants in 2008 came from living donors. The vast majority of these involved relatives of the recipients; less than 8% came from unrelated donors. In 2008, Brazil's health minister proposed banning unrelated donors in kidney transplantation. A large number of the over 35,000 Brazilians on the waiting list for a kidney would be denied a transplant without the use of unrelated donors. Brazilian culture has a unique feature- the "informal family"-that is not legally recognised as a family entity and is bound by affection rather than genetic or legal ties. It is vital that Brazil establishes a regulated, standardised, and ethical system of organ procurement; creates awareness about transplantation in physicians and the public; upgrades facilities and standardises medical care, and enforces legislation for transplantation. However, outlawing the use of unrelated donors would result in injustice for many patients who seek kidneys.

Introduction

Brazil, which occupies nearly half the land area of South America, is the fifth most populous country in the world. The last census in 2007 revealed a population of 189,987,291. Brazil's current constitution defines it as a federal republic. The country also boasts the world's tenth largest economy at market exchange rates. Economic reforms have given the country new international influence. Brazil is a founding member of the United Nations

and the Union of South American Nations. It is a predominantly Roman Catholic, Portuguese-speaking, and multiethnic society.

Of course, Brazil has had some struggles as well. The country is grappling with substantial problems characteristic of the developing world, including enduring poverty, urban violence and widespread social inequity. Brazil has among the highest income inequality discrepancies and poverty rates in the world, although these values are declining. In March 2002, 18.5 million Brazilians were living in poverty. In June 2009, this number had dropped to 14.4 million. The Gini Index, which measures the degree of inequality in the distribution of family income in a country, placed Brazil in the tenth worst position in the world in 2005.

The history of kidney transplantation in Brazil began in 1965, when the first related living donor transplant took place in Sao Paulo (1); one year later, the first deceased donor kidney transplant took place in Ribeirao Preto. Since then, Brazil has established a public programme and now has the largest public kidney transplantation system in the world (2).

Brazilian kidney transplantation in numbers

In 2008, the number of kidney transplants reached a historically high number of 3,780, the second highest in the world. However, when we divide this number by the nation's population (20.5 per million), the value is frustratingly low compared to those in the developed countries. An estimated 35,000 Brazilians are on the waiting list for a kidney transplant (3).

The world's largest kidney transplantation centre is located in Brazil (3). In 2008, 136 renal transplant centres were active in Brazil, although 229 were registered with the Ministry of Health. The majority of these centres are located in the southern and south-eastern parts of the country.

Living kidney donors in Brazil were responsible for 46.2% of kidney donations in 2008 (4). The vast majority of living kidney transplants involved relatives of the recipients, less than 8% came from unrelated donors. In 2008, the number of deceased donors per million population — 7.2 per million — was very low (3).

Further, there is no active programme in Brazil on live kidney donation from what are currently termed non-directed donors or altruistic donors. These include live-donor paired exchange programmes (exchanges involving two donors who are incompatible with their intended recipients so that each donates to a compatible recipient) and live-donor/deceased-donor exchange programmes. In the latter, one donor who is incompatible with his intended recipient donates his organ to the highest ranking appropriate individual on the centre list, while the incompatible recipient for whom the donor kidney was originally intended receives the right of first refusal for the next ABO identical or O-type deceased-donor kidney available. These programmes have resulted in an increase in the number of living donors in the United States (5).

The Brazilian legislation

1997's Rule 9.434, Article Nine of the Federal Legislation states, "Individuals are legally able to dispose of free tissues, organs and body parts, for therapeutic purposes or for transplantation to a spouse or blood relatives within the fourth degree, inclusive, pursuant to § 4 of this article, or any other person, by judicial authorization..." Based on the words "or any other person, by judicial authorization", some centres perform living kidney transplants from unrelated donors.

In 2008, Brazil's health minister placed before the legislature an ordinance under public consultation from the Technical Regulation of the National Transplantation System, approved by Ordinance 3.407/GM of 1998, regarding the need to upgrade, improve and standardise the operation of the National Transplant System in Brazil. The text included the following statement: "We will only accept living unrelated donors for recipients whose time on the waiting list has been more than 1,350 days..."

Why outlaw unrelated donors in Brazil?

It is abundantly clear that the Brazilian government is opposed to any type of transplant commercialism. In a country with high income inequality, this could raise significant ethical issues. Transplant commercialisation would only introduce larger

disparities into the population. This is very different from a country like Sweden, where there is very little income disparity and the literacy rate is above 99%.

On the other hand, outlawing unrelated donation could be devastating for the over 35,000 patients who are on the waiting list for a kidney, and others who were never on the list because they already have identified unrelated donors. Keeping patients on dialysis for approximately four years while on the waiting list and then assigning an unrelated donor for transplantation could also result in poor prognoses for recipients. The medical literature shows that increased time on dialysis is associated with lower quality in resulting grafts and diminished patient survival (6-8).

The adjusted five-year allograft survival for an unrelated kidney transplant is no different from the survival achieved with the transplantation of a kidney from a parent or child of the recipient or from a 50% identical sibling (9). Moreover, a kidney transplant from haploidentical¹ parents or siblings has outcomes similar to those from a human leukocyte antigen (HLA)-mismatched spouse or friend (10).

The life spans of kidney donors are similar to those of persons who have not donated a kidney (11). The risk of end-stage renal disease does not appear to be increased among donors, and their current health seems to be similar to that of the general population. In addition, the donors' quality of life appears to be excellent (12).

The poorly served population

A large number of Brazilians would be poorly served without the use of unrelated donors. In the past few decades, Brazilian culture has developed a unique feature, the "informal family". Informal families are not legally recognised "constitutionalised family entities". The patriarchal family, upon which much of Brazil's civil legislation was modeled in the 20th century, is in crisis. Affection, rather than genetic bonds, has come to characterise many families in the country (13).

Gay people would be poorly served because, in Brazil, federal law and the constitution do not recognise same-sex couples as

spouses, due to the definition of marriage as being between a man and a woman.

Foster children with no ties to natural or adoptive family in Brazil are often from the lower social strata and may be raised by neighbours or others without legal recognition.

Unrelated individuals who live together permanently but are not wedded have generally decided to live with one another based on affection and mutual help, rather than for sexual or economic purposes.

A concubine union, in which there are impediments to an individual marrying one or more partners, is another example of an informal family that would be poorly served without the use of unrelated donors.

Conclusion

It is vital that Brazil establishes a regulated, standardised, and ethical system of organ procurement, creates awareness of transplantation in physicians and the public, upgrades facilities and standardises medical care, and enforces legislation for transplantation. On the other hand, outlawing the use of unrelated donors would introduce greater inequity for many patients who seek kidneys.

The aphorism "*primum non nocere*" (first do no harm) was introduced to guide physicians in making difficult and potentially hazardous decisions; it should always be kept in mind when dealing with live kidney donors. Offering information to potential donors is a key point in the decision-making process, along with giving individuals the liberty to decide, on the basis of this information, what is best for them. Whether the individual is related or unrelated to the recipient makes no difference to the level of potential harm to the donor. If the medical literature establishes greater risks associated with being a live kidney donor, living kidney donation should be discontinued.

The first article of the Universal Declaration of Human Rights says, "All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should

act towards one another in a spirit of brotherhood.” Adopted by the United Nations General Assembly in Paris in 1948, the statement captures the spirit of what should be acceptable in organ donation. We should never alter this principle or discriminate between donors based on their family relationships. A physician has the duty to avoid harm. We should always think of the donor as a person who could benefit someone, and, as such, should offer pertinent information and the autonomy to make a decision about one’s body.

Note:

- ¹ ‘haploidentical’ means having the same alleles at a set of closely linked genes on one chromosome.

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Pakistan's experience with kidney transplantation and trade: a call for international solidarity

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Abstract

Pakistan has taken a long and tortuous road towards curbing the trade in organs within its borders. Yet, despite the phenomenal gains, several challenges remain in this area. For example, robust and sustainable deceased donor programmes must be established to meet the needs of a country which has a high prevalence of kidney disease and failure. Further, it is necessary to offer an alternative source of organs for transplantation to desperate patients who resort to buying these from the "market". Cultural factors and religious beliefs about the sanctity and inviolability of the corpse, as well as the lack of public and professional education regarding the procurement of organs from the deceased, pose considerable barriers that must be surmounted. We believe it is equally important that transplant professionals and the governments of affluent countries consider measures to discourage, if not prevent, their citizens from travelling to impoverished countries such as Pakistan to buy organs. Without a commitment, ethical and legal, to international solidarity in this matter, the goals that are already difficult for developing countries to achieve, ie, establishing deceased donor programmes and bringing an end to organ trafficking, will be even harder to achieve.

"Why should I give *takleef* (harm/trouble) to my family if I can buy a kidney?"

(Patient awaiting kidney transplant)

Pakistan, a low-income country with a population of 185 million, has been waging a long battle, against great odds, to counter tourism

and trade in organs in the country. For over two decades, patients from different countries, particularly from the Middle Eastern region, have been travelling to Pakistan for kidney transplantation using kidneys bought from its most disadvantaged citizens. The struggle against such practices has united and galvanised concerned members of the medical community, together with the media, leaders of civil society, members of the judiciary, including the former Chief Justice of the Supreme Court of Pakistan, and human rights organisations (1 - 4). A Transplant Ordinance was passed in 2007. Ratified into law in 2010, it criminalised the purchase and sale of organs. The result was a dramatic drop in the number of transplants carried out with vended kidneys. However, complete control is yet to be achieved. We believe that one of the major hurdles is the absence of deceased donor programmes, due to which many desperate patients take recourse to kidney vendors.

Our experience also highlights the fact that national efforts, in isolation, can go only so far in preventing organ trafficking which, by its very nature, recognises no borders. Poor countries such as Pakistan cannot win this battle single-handedly. There is need for a consensus among the international transplant community that healthcare professionals and the governments of affluent countries, from which transplant tourists originate, also have a moral and legal responsibility to take proactive steps to discourage/deter their citizens from engaging in this practice. We believe that the elimination of transplant tourism requires solidarity among transplant professionals across the globe, a joining of hands, that goes beyond signing international declarations. The recent steps taken in Israel show that affluent countries can also adopt effective regulatory measures to reduce the number of their citizens travelling to other countries for transplants (5, 6).

This article provides a brief overview of the steps Pakistan has taken since the 1990s to control the kidney trade and outlines the local hurdles that have been overcome in this process. We argue that overcoming reluctance to deceased donation and establishing deceased donor programmes are essential for developing countries aiming to achieve self-sufficiency in transplantation, and that doing so can also assist in reducing commerce in organs. Achieving self-

sufficiency is a recommendation of the World Health Organization (WHO) and was endorsed by the Declaration of Istanbul at a meeting attended by over 90 international transplant-related organisations and 152 delegates (7,8). We will also elaborate on our belief that it is the ethical responsibility of medical communities and associations concerned with transplantation to undertake proactive measures, such as educating patients with renal failure on the illegality of transplantation with vended organs and the risks connected with it. Finally, we will discuss the need for national governments to consider laws that discourage their citizens from cross-border organ tourism.

Overview of kidney transplantation and trafficking in Pakistan

The long road to a transplant law: In Pakistan, the first kidney transplants occurred in the late 1970s, when neither relevant national laws nor institutional regulatory mechanisms were in place. However, it was not until the mid-1980s that a systematic, organised kidney transplantation programme, using living related donors, was initiated in the Sindh Institute of Urology and Transplantation (SIUT), a public sector institution in Karachi (9). By the 1990s, due to its lucrative nature, kidney transplantation began to be increasingly offered by private hospitals around the country. Media reports began to emerge about kidneys being bought or “stolen” from impoverished labourers and kiln workers. Following the first Gulf War in Iraq (1990) and the passage of the Indian Transplant Law (1994), the stream of affluent patients with renal failure, hailing from different countries, shifted towards Pakistan in search of kidneys. By the turn of the century, private sector hospitals, mostly in the province of Punjab, were openly advertising “transplant packages” to lure foreign patients and Pakistan had acquired the reputation of being the “kidney bazaar” of the world (10, 11).

In the first decade of this century, a national campaign led by SIUT grew into a national movement to pressure the government to enact laws on organ transplantation and the criteria for brain death, as well as to pass legislation prohibiting trafficking in organs. The

movement was backed by a cadre of healthcare professionals and organisations, as well as prominent members of civil society. Journalists and the local media played a key role in keeping the issue alive through interviews with kidney vendors. Transplant physicians and faculty members from the Centre of Biomedical Ethics and Culture, SIUT, in Karachi carried out ethnographic and social studies which brought to light the abysmal condition of those who had sold their kidneys. The results of these studies were highlighted in the local press and international journals (12, 13). Additional pressure was brought to bear on the government through collaborations between the faculty and WHO, the Asian Task Force on Organ Trafficking, and the Istanbul Group Against Organ Trade.

Subsequent events: In 2006, persistent recalcitrance on the part of government officials, who were supported by an influential pro-organ-trade lobby that was opposed to a transplantation law, led the then Chief Justice of the Supreme Court to take suo moto notice of cases of the purchase and sale of kidneys in the country. He ordered the government to take immediate steps against these practices. A year later, the Transplantation of Human Organs and Tissues Ordinance was promulgated by a Presidential decree. The Ordinance criminalised commerce in organs and prohibited the transplant of organs in foreigners. It provided for heavy penalties for all parties involved in these practices. The Ordinance also instituted a national body, the Human Organ Transplantation Authority (HOTA), to register and monitor institutions offering transplants in Pakistan. According to a personal communication by HOTA, it had registered 25 institutions since its inception in September 2007 until December 2012. During this period, a total of 3601 transplant activities were registered. These included kidney, liver, cornea and bone marrow transplants.

Several attempts were made by the influential pro-organ-trade lobby to weaken the Ordinance before it could become law. In 2008, a private member bill was introduced in the National Assembly, but this was eventually withdrawn following strong anti-lobbying efforts. Perhaps the most serious challenge was a petition filed in 2009 in the Federal Shariat Court (FSC) against

members of the Federal government. The Constitution of Pakistan forbids the enactment of laws contrary to the Qur'an and Sunna, and the petitioners claimed that certain clauses of the Ordinance (including the prohibition of financial compensation and transplantation in foreign patients) were contrary to the teachings of Islam. Over the course of a year, the FSC held several hearings, which were open to the general public, after which the justices gave a unanimous ruling rejecting the petition (14).

The promulgation of the Ordinance initially led to a precipitous drop in the number of transplants (estimated to be around 2000 or more annually) using vended kidneys. However, from 2008 onwards, sporadic reports began to appear in the media about foreigners who had undergone transplantation in private clinics in Punjab. Complaints were also received from colleagues in the field of transplantation in the Middle East (Kuwait, Oman, Saudi Arabia, the United Arab Emirates, Egypt, Palestine, etc.) after they were consulted by patients who had developed severe complications following kidney transplants carried out in Pakistan. Attempts to obtain the details of these cases from the healthcare professionals of these countries in order to pursue investigations in Pakistan were generally unsuccessful due to concerns relating to "patient confidentiality". In 2009, however, following the failure of HOTA to take appropriate action, SIUT again approached the Supreme Court directly, drawing its attention to two private hospitals in Punjab (Lahore and Rawalpindi) that were involved in carrying out transplants for foreigners. The Chief Justice issued a warning to the personnel of both hospitals (vide order 9.7.2009) and the hospital in Lahore subsequently discontinued all transplant services. However, reports suggest that the institution in Rawalpindi as well as some fly-by-night private clinics in Punjab, are still surreptitiously carrying out transplants in non-Pakistani citizens.

The Ordinance was finally ratified unanimously into national law by the National Assembly and the Senate in 2010 (15). Attempts were initiated to register transplant institutions and obtain annual reports from them, but overall, the attempts of the federal HOTA within the Ministry of Health remained largely unsatisfactory

in terms of investigating and taking punitive action against institutions suspected of trade in organs. In September 2011, a joint petition (Constitution Petition No. 55 of 2011) was filed in the Supreme Court against the Federation of Pakistan and provincial health secretaries by members of civil society, including leading lawyers, physicians (including faculty members of the SIUT and CBEC), journalists, philanthropists and the chair of the Human Rights Commission, pleading that the trade in organs violates the fundamental rights of the citizens of Pakistan. The results of the petition are pending, although several hearings have taken place. It is obvious that the road to ethical transplantation has been riddled with challenges (16).

Recent developments: In 2010, via Amendment 18 of the Pakistan Constitution, many services and regulatory functions were shifted from federal to provincial jurisdiction. This includes health services, such as those offered by the federal HOTA. Due to continuing concerns about commercial practices related to organs, in August 2012 the Chief Justice ordered that provincial HOTAs be instituted in Sindh, Punjab, Balochistan and Khyber Pakhtunkhwa within six weeks to oversee and regulate human organ transplantation (17, 18). At the time of writing this article, all four committees had been constituted via an Act of Parliament. The body in Sindh (SHOTAs) has started functioning and held its first meeting recently. It is hoped that the provincial HOTAs will be far more effective than their federal predecessor.

Need for deceased donor programmes

In many countries in the West, deceased donor programmes are the source of a significant number of the organs used for transplantation (19, 20, 21). In contrast, most developing countries do not have deceased donor programmes in place due to the absence of appropriate infrastructure and logistics, cost issues, and lack of trained medical and paramedical health professionals. Organs for transplantation procedures are obtained mostly from living donors, related and unrelated. This also holds good for kidney transplants, which are now among the most frequently performed procedures in these countries. Recently, some developing countries have taken initiatives to introduce deceased donor programmes. Reports from

Shiraz, Iran and Tamil Nadu, India suggest that the introduction of such programmes has not only increased the number of kidneys available for transplantation, but may also be helping to decrease the number of illegal and unethical transplants using kidneys that have been bought (22 - 26). There are some early indications that China's move to initiate transparent, voluntary deceased donor programmes may help to eventually rid the country of the practice of using executed prisoners as a source of organs – a practice which has made China a pariah within the international transplant community (27).

Pakistan is yet to take organised, systematic, national or provincial measures for the introduction of deceased donor programmes. In the three decades since kidney transplantation began to be carried out in the country, 26 kidney transplants from deceased donors have taken place, all in SIUT, using kidneys flown in from Europe, courtesy of the Eurotransplant Foundation (28). During this same period, only four Pakistanis, declared brain dead, have donated their kidneys for transplantation. In these cases, the family members had approached SIUT, (in one case, Shifa Hospital in Islamabad), stating that the deceased had expressed a wish during conversations at some stage in their life that their organs be donated in the case of their death. These are isolated cases and the situation will not change unless organised efforts are made to educate the public and established systems are put in place for potential donors and their families to approach. A neurosurgeon in Karachi estimates (personal communication) that over 1000 individuals are pronounced brain dead in the five busiest hospitals of the city every year. Needless to say, many of these individuals could have been potential deceased donors. At present, there is no mechanism in place to tap potential sources of organs for transplantation. The situation is compounded by the dearth of trained critical care healthcare professionals and counselling teams that can engage with the families of such patients.

There is, however, increasing awareness among transplant professionals in Pakistan that establishing deceased donor programmes is an essential and not an optional step. It is being recognised that such programmes are necessary for augmenting

the insufficient number of transplantable kidneys available from living donors in a country in which the estimated prevalence of renal disease is 100 per million population, with a large number of patients progressing to end-stage renal failure each year (29). On the basis of the experience of Iran and India, it is also believed that greater availability of organs from deceased donors may help to control kidney trafficking in the country. However, a great deal of spadework is required before this objective can be achieved. This includes training and educating healthcare professionals in the critical and intensive care units of the relevant institutions on the criteria for brain death, as well as the ethical and sociological factors that are central to interacting with grieving families. Further, systems that are transparent and free from conflicts of interest will need to be established. This can be achieved through a clear separation of those providing end-of-life care to potential donors, the transplant team itself, and others responsible for approaching the families to assess their willingness to allow the donation. In the absence of these steps, the transplant community risks losing the trust of the public further. As it is, due to Pakistan's history of commerce in kidneys, some believe that physicians and their institutions engage in dishonest practices to obtain kidneys from the impoverished and transplant them into the rich for monetary gain (13).

A crucial and equally important step will be to gain the confidence of the public, as well as public acceptance of and support for the programmes. For this, healthcare professionals – in person, through civil society organisations, and using the popular press and media – will have to involve themselves in organised, regular and sustained activities to interact with the public about deceased organ donation. This is necessary not only to provide information on what deceased organ donation involves, but also to convince them that donation following death is not a “medical” issue, but one of shared social responsibility of citizens towards one another. In the absence of such an effort, robust deceased donor programmes will not be possible. The importance of this approach is illustrated by the experience in Spain, which has the highest rate of deceased donation in the world, and more recently, that of Tamil Nadu in India (23, 30).

Pakistan has a majority Muslim population and it is reported that there is a reluctance among them to embrace deceased organ donation, often on the basis of religious interpretations (31, 32). A major issue, therefore, will be to understand their sentiments and tackle them with sensitivity. This attitude of the public is reflected in a couple of surveys undertaken in Pakistan (33, 34). The reluctance based on religious views, combined with a lack of knowledge of what deceased donation entails, also became evident in the recent empirical research we undertook in Karachi. We found that whereas our interviewees were familiar with, and mostly supportive of, living kidney donation, many believed that the human body belongs to God and is given to humans on trust, and that removing organs from a corpse is equivalent to its mutilation – an act strictly prohibited in *Sharia* (Muslim law) (35).

This finding is ironical in the light of the fact that the Muslim *ulema* in renowned Islamic centres have approved of the criteria for brain death, and have pronounced (as majority opinion) that both living and deceased organ donations are not only permitted, but are also praiseworthy acts. This is in consonance with the view advocated by Muslim transplant professionals (36, 37). On the other hand, as found by our studies, most Muslims' beliefs about right and wrong and about permitted and prohibited acts in *Sharia* law are more in the nature of a socially constructed understanding of Islam. This understanding has been passed down the generations and influenced by the opinions of local religious leaders rather than by juristic edicts originating from distant Islamic centres. Unless attempts are made to proactively and effectively engage with cultural and religious opposition, it will be difficult to get the Pakistani public to "own" and support deceased donor programmes.

Sharing the burden

Countries like Pakistan must continue to address the problems of inadequate infrastructure, lack of mechanisms for oversight and corruption, which feed the lucrative transplant business. All these factors combine to make the consistent enforcement of the transplant law difficult and the most disenfranchised citizens thus continue to be exploited. However, the difficulties are

compounded by the absence of active measures – legislation and ethical policies, at the government and professional levels – in other countries to at least discourage, if not prevent, their citizens from travelling abroad to buy organs.

In this context, it is encouraging that the Declaration of Istanbul Custodian Group (DICG) is considering the issue of extraterritorial jurisdictions relating to transplant tourism, and may possibly arrive at some guidelines.

“Rights” of patients versus responsibilities to others: Those who advocate commercial transactions in human organs, whether as “regulated” markets or cross-border transplant tourism, use the arguments of autonomy, the rights of the individual and freedom of choice to justify the practices of buying and selling organs. In this paradigm, the principles of solidarity and social responsibility, indeed even the laws of countries, are marginalised. When the affluent buy organs from the impoverished on the basis of the perceived primacy of freedom and the right of individuals to seek treatment, regardless of all else, the existing global inequities are perpetuated and intensified. It is also ironical that in many instances, such patients are citizens of countries in which buying and selling of human organs are illegal, and they travel for transplantation to another country where such practices are also against the law as this exploits those most vulnerable individuals. The lack of measures to hold such patients responsible when they return home is lamentable, and the tendency to blame the “host” countries for not doing enough smacks of hypocrisy and double standards.

An individual’s right to privacy and the confidentiality of the physician–patient relationship are also cited as reasons for the inability/reluctance to provide information to aid the investigation of those travelling abroad for illegal transplants (as we have faced in Pakistan). However, privacy and confidentiality are not absolute principles. We feel that transplant professionals and their associations must begin to discuss how to balance these principles against the costs to the healthcare systems of their countries and to the “host” countries. This is a necessity because many patients return to their native country with several complications, and

also because organ tourism harms countries that are struggling to control trafficking in organs within their borders. In our opinion, claims to privacy should not outweigh fairness and justice.

Transplant professionals' responsibilities towards patients: It is well established that patients undergoing transplantation with vended organs suffer relatively higher rates of complications, including life-threatening infections, graft failure and death (38, 39). It is not clear how well these patients know and understand this. It is also not clear whether, in their desperation for a transplant, they are aware that the practice is illegal and that they and the vendor are liable to severe punishments, including jail sentences, if caught. We have heard some of our Pakistani patients mentioning that they are contemplating buying a kidney; it is quite possible that physicians in other countries have had a similar experience. In our opinion, national transplant associations should require physicians to disseminate information on the risks faced by patients seeking transplantations with vended organs, as well as the illegality of this practice. This should be accompanied by clear expressions of disapproval and discouragement of such practices by physicians while dealing with their patients. A recent publication from Canada presents a policy statement which stresses the ethical responsibilities of transplant professionals and lists steps that will result in greater involvement of these professionals (40). While we are not in favour of denying care to patients who return critically ill after undergoing an illegal transplant, it should still be possible to take an ethical stand against this practice during interactions with such patients, as well as those suspected of planning to travel abroad for illegal transplants.

Responsibility for national self-sufficiency in transplant programmes: The international transplant community is unanimous that commerce in human organs is profoundly unethical and has been able to influence governments, as in Pakistan, to pass laws declaring it illegal. WHO, the Istanbul Declaration and other international accords also stress the importance of attaining national self-sufficiency in transplantation through robust living and deceased donor programmes based on altruistic donations (7, 41, 42). Transplant tourism remains a significant hurdle in

achieving self-sufficiency, not only in the developing countries to which the tourists travel, but also in the countries from which they originate. We believe that transplant professionals and associations in countries that are signatories to international agreements have an ethical (and legal) obligation to take appropriate steps to prevent their citizens from travelling abroad for transplants.

We realise that it may be difficult to formulate one, uniform legal solution that can be applied across all countries to prevent citizens from travelling for transplants, or arrive at a uniform set of measures to make those returning with illegally transplanted organs accountable. However, we can at least reach a consensus that these practices are wrong and need to be addressed. The power of moral consensus within a group can often pave the way for legal steps.

Summary

Pakistan's experience and its struggle to stem the exploitative trade and trafficking in kidneys bear many similarities with the situation in other impoverished countries. It took Pakistan several years to pass a transplant law criminalising such practices and many internal challenges had to be overcome in the process. The eventual success of the efforts can be attributed to the fact that members of the public, the judiciary and media joined hands with the healthcare professionals and associations concerned, and also, to collaborations with international transplant societies and organisations such as WHO and the Istanbul Group against Organ Trade.

However, Pakistan's battle against organ trafficking is not over yet. It is essential to develop robust deceased donor programmes to increase the number of organs available for transplantation, and to offer an alternative to desperate patients who resort to buying organs from the market. This will require cohesive, well thought out and organised strategies to educate, mobilise and involve people from all sectors of society, from the public to the professional domains. Our studies reveal that there is considerable resistance among the public against the donation of organs following death due to myths and misconceptions arising

out of religious and cultural beliefs. It will be difficult to sustain deceased donor programmes unless concerted efforts are made to win over the public by addressing their sentiments in a sensitive manner, and to convince them that such donation is a matter of the social responsibility of one citizen towards another rather than a “medical” issue.

While Pakistan must continue its efforts to improve the effectiveness of the transplant law and make its implementation more transparent, it is the moral responsibility of the international community to push the governments and healthcare professionals of “recipient” nations to consider ethical and legal measures to discourage their citizens from breaking their country’s laws against trade in organs, as well as those of the countries to which they travel to buy organs. Trade and trafficking in organs survives on the strength of transnational movement. Perhaps international steps similar to the laws curbing cross-border trafficking of humans could be considered. The absence of such steps is another hurdle for developing countries trying to achieve national self-sufficiency in organ transplantation through altruistic living and deceased donors programmes, an objective unanimously endorsed by the international transplant community.

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Deceased donor renal transplantation and the disruptive effect of commercial transplants: the experience of Oman

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Abstract

The Oman Renal Transplantation Program was established in 1988 as a joint venture between Sultan Qaboos University and the Ministry of Health. It began with both living related donor (LRD) and deceased donor (DD) transplants. Over the next nine years, while the LRD programme progressed relatively well, there were only thirteen DD transplants. Two of the DD kidneys were obtained from overseas via an active collaboration with the Euro-transplant organisation, and one DD kidney was obtained from Saudi Arabia within the Gulf Cooperative Council exchange programme. The rest of the DD kidneys were obtained in Oman. The Omani DD programme, although it was a pioneering effort in the Gulf region at the time, was not entirely sustainable. In this paper, we focus on the challenges we encountered. Among the major challenges was the absence of resources to establish a dedicated DD programme and particularly the failure to develop a cadre of dedicated transplant coordinators.

Background

End-stage renal failure is managed by dialysis or transplantation, and patients have a right to them where these modalities can be provided. Because of the almost universal shortage of donors, most successful programmes depend on both related donors (either living related donors (LRD), or living unrelated donors (LUD) and deceased donors (DD)). In most developing countries, it has been

difficult to establish DD programmes because that requires a huge amount of government support, not least by providing the legal framework and establishing brain death criteria as constituting death – the latter to be done unequivocally, with the population being aware and participating in the process. In some countries, there has been, for a long time, a lack of clarity on this issue, based often on religious or cultural interpretations. In Oman, we did develop transplant regulations in 1994 that were endorsed by formal ministerial decrees. Though the civil authorities have accepted the brain death criteria, the religious authorities have not yet publicly accepted them. As a result, although organs have been retrieved from deceased persons on rare occasions, the situation has become equivocal. Self-sufficiency in organs for transplantation is not possible at the moment without an active DD programme. The absence of such a programme will ultimately lead to the flourishing of disruptive transplantations which include rampant commercial transplants in neighbouring countries, and on rare occasions, transplants from executed prisoners in countries such as China.

The Omani experience

The Oman Renal Transplantation Program was established in 1988 as a joint venture between the two major academic and service institutions of the country, namely Sultan Qaboos University and the Ministry of Health. Transplantations were performed using both DD and LRD. Relationship was defined by blood or marriage. We did not, and still do not, accept LUD for fear of hidden commercialism, although most developed countries have now accepted this mode of donation with proper ethical and legal measures (1-4). This policy may need to be revisited in the near future. Some DD transplants were performed in very young children of less than 2 years of age with excellent results; and one of them still has a functioning graft 20 years after the transplantation. Thirteen DD transplants were performed during the period 1988–1997. During that same period, we performed 60 LRD transplants. Subsequently, another two DD transplants were performed in Oman and eight more DD transplants were performed on Omanis who were living abroad, mainly as students

in the USA and the UK, and when they returned we looked after them. Our total experience in this period, therefore, is of about 23 DD transplants. The programme has evolved now to being mainly one of LRD transplants because of deceased donation becoming unsustainable.

Before we look at the challenges for sustainability, let us mention the components of success for even the small number of transplants that were performed under difficult conditions:

1. *Competency, collaboration and team spirit:* The cooperation among dedicated and expert surgeons and physicians was crucial both in the establishment of the programme and in its implementation. The programme began when the medical services in the country were relatively young and when it was difficult to convince people to donate blood, and so there were many administrative, logistic and societal issues that had to be addressed.
2. *Ethical expertise:* There were many new ethical issues to address in both the LRD and DD arms of the programme. These were practical ethical issues that were addressed using sound, universal values and guidelines. As a result, we were able to establish a measure of confidence among administrators, donors and recipients, and their families. The patients did perceive the caring team as being empathetic. Good communication with patients and their relatives was a priority.
3. *Donor procurement:* In the absence of a structured entity and dedicated transplant coordinators, DD organ procurement was not developed as much as the other components of the programme, which evolved to focus more on LRD transplantation. Nevertheless, serious efforts were made to engage medical and nursing staff in intensive care units but the number of transplants attests to the modest success we were able to achieve. A critical care head nurse at a hospital outside the programme was most helpful in identifying potential deceased donors, largely because of her European experience in organ retrieval.
4. *Regional and international cooperation:* These were extremely valuable, especially at the beginning of the DD programme.

We obtained three DD kidneys through Euro-transplant and the Saudi Center for Organ Transplantation (SCOT). However, these were exchange programmes and we were not able to reciprocate.

Challenges to programme sustainability

- 1. The absence of a dedicated entity for DD transplants:* Chief among the challenges was the absence of a dedicated entity for DD transplants. This could be due to a perception by the authorities of the cultural prematurity of such a challenge and the ease with which certain patients were able to get LUD transplantation from a neighbouring country. Since so many patients required transplants and it was easier to establish an LRD programme, we allocated more resources towards that, while we continued discussions with the authorities for the acceptance of brain death criteria. LRD transplantation was facilitated by the large sizes of nuclear and extended families in Oman—a similar situation exists in all the Gulf countries. Attempts to expand the programme to include a structured DD component with dedicated transplant coordinators was beset by many barriers, despite introducing educational programmes such as the EDHEP (European Donor Hospital Education Program, which later became “Donor Action”) in 1996 and total procurement management in collaboration with the University of Barcelona in 2008. Many nurses and doctors were sent for coordination training to Turkey, Saudi Arabia, Kuwait and Spain, but we could not convert that experience into results because a structured entity was lacking. Had we succeeded in establishing a structured DD component, it is very likely the numbers of DD transplants would have been significantly higher. However, we continue with our advocacy to the authorities about the vitality of the programme and the need for their public support.
- 2. The impact of disruptive rampant commercial transplants:* Our study in the formative stages of the programme resulted in one of the first publications to establish the risks of unregulated commercial transplants (5), followed by a number of contributions to the debate about living donors (6, 7). At

that stage, we had not yet encountered on a large scale the disruptive effects on our own programme as a result of our patients with end-stage renal failure going to purchase kidneys overseas. This disruption of our programme became, and continues to be, a major hindrance to developing both our LRD and DD components, reducing the pressure on the authorities to provide more resources for our own transplant programme, particularly for the DD component. We have been supportive of The Declaration of Istanbul (DoI) (8), which has set ethical guidelines and a framework for transplantation. The DoI is strongly against patients travelling outside their own countries to buy organs (transplant tourism). High and realistic hopes were hinged on the DoI. Indeed, immediately after the DoI, commercial transplants decreased from 49 in 2007 to 30 in 2010. Even more impressive was that, during the same period, transplants performed in Oman increased from 12 in 2007 to 23 in 2009 (9).

Discussion

An interesting question that arises is with regard to which should be done first: attempting to ban transplant tourism or establishing a strong and dedicated DD unit with professional transplant coordinators? While we cannot definitively answer this question we can cite the successful experience of our neighbouring countries.

The Saudi Center for Organ Transplantation (SCOT) was established with dedicated resources for both LRD and DD transplants. While they also suffered from the disruptive effects of transplant tourism, their dedicated DD component enabled them to develop a strong DD programme, which in turn undermined transplant tourism to a great extent (10).

Another good example is Iran. While the programme there was and is still based mainly, but not solely, on LUD, it has several unique features. It is officially regulated by the state (11). The work-up of donors and recipients, kidney allocation and the reward is directed by a non-profit organisation. Transplants are restricted only to Iranian nationals, and transplant tourism is forbidden. In principle,

the system does not breach international ethics guidelines and has become widely accepted by the international community. It has also permitted bridging towards DD transplants. The Iranian DD programmes are also flourishing, mainly in Shiraz and Tehran. These DD programmes have excellent results (12) and are not only thriving but show constant improvement. We believe that if transplant tourism could be banned, and local transplant programmes are well supported, then it would be possible to achieve an acceptable measure of self-sufficiency through both LD and DD transplants.

We have also been challenged by the issue of unsuitable living donors: obesity, hypertension and diabetes are conditions that are increasing exponentially in many parts of the world, but more so in the Gulf countries (13). Many of the potential donors might not be suitable for donation, or donation may present a long-term risk for their health (14-17). We have analysed the reasons for exclusion of potential donors from donation for the

Table 1 :
Causes of preclusion of donors and recipients

Potential recipients	70
Potential donors	99
Recipients transplanted	50.7%
Rejected or declined donors	58 (58.6%)
Accomplished transplantations	35
Medical causes in the 99 donors (35%)	
Hypertension	10
Obesity	5
Urological anomalies	4
Proteinuria	4
Unknown diabetes mellitus	4
High liver enzymes	2
Viral hepatitis	2
Others	5
Non-medical causes in the recipient (15%)	
Transplant tourism	11
Others	4

period January 2006 through July 2008. About 50% of potential donors were declined (18). Similar high rates of exclusions have also been observed for kidney and liver donors in the UK and the USA (19, 20). The reasons for donors' and recipient's preclusion in Oman are summarised in Table 1.

Another important point is the role of public engagement. The possible resistance of our populations to DD transplants, while it could be real, should not be overestimated (21-25). We have recently carried out a survey to examine the attitudes of the Omani population towards transplantation (26). The results were not overtly discouraging (Table 2). In Oman, public awareness and public education campaigns have been shown to work well

Table 2 :
Question: Would you donate your organs after death?

Education	Yes (%)	No (%)	Don't know (%)
Primary	47.1	23.5	26.5
Postgraduate	51.9	29.6	18.5
University	36.4	39.9	23.1
Secondary	42.0	44.0	14.0
Average	40.8	38.5	20.

in increasing childhood vaccination rates and in increasing birth spacing. This would suggest that similar measures might succeed in increasing life-saving programmes such as organ transplantation. The experience of our neighbouring countries such as Saudi Arabia (27), Kuwait (28), Iran (12), and Turkey (29) give us hope.

Conclusion

DD transplants are technically feasible and are necessary in developing countries. To succeed, such programmes require a dedicated organisational unit with competent coordinators. Legal, social, psychological, and cultural barriers may be overcome with proper advocacy, awareness, education, and engagement. Autosufficiency in organs through an active deceased donation

programme would also be the best means to deter commercial transplants.

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Reaching self-sufficiency in deceased organ donation in Asia: harsh realities and ethical concerns

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Although trials to exchange failing human organs with new ones started in the beginning of the past century, the first breakthrough came in December 1954, when the first successful kidney transplant between identical twins was performed in Boston, USA, by Dr Joseph Murray. Since then transplantation has come a long way to be recognised as the treatment of choice for thousands of new patients afflicted yearly with organ failure around the world.

The World Health Organisation (WHO) estimates indicate that over a million transplants are required every year to satisfy the global need, but the actual number of transplants does not exceed one hundred thousands, ie only 10% of the need (1). There are many causes for this disparity including economic, social, and organisational factors but shortage of organs is the restricting factor in many parts of the world. Needless to say that in Asia this disparity is most obvious (1, 2).

Sources for organs

Organs come from two sources: living and deceased human beings. Living donors are limited to donating either one of double organs (kidney) or part of a single organ such as the liver, whereas multiple organs and tissues can be recovered from a single deceased donor allowing multiple transplants from one source. In the developed world, both sources are used to the maximum in order to decrease the gap between availability and demand for organs, leading to high rates of transplantation of various organs, especially in Europe and North America.

On the other hand, deceased donation is uncommon in Asia and the majority of transplants are limited to organs that can be obtained from living donors. This limitation has severely affected both number and type of transplants performed.

Consequences of organ shortage

The success of transplantation in saving lives and improving its quality has increased demand for organs and created an illegal and unregulated market in many parts of the world. WHO estimates that 10% of all kidney transplants in the world come from paid donors.

These practices are more common in regions with a shortage of deceased organ donors when living donors cannot satisfy the need. An abundance of poor and vulnerable people in many Asian countries, willing to sell their kidneys (3, 4) in return for a few thousand dollars, created a wave of transplant tourism since the 1980s. A large number of patients, from well off countries, travel to countries such as India, Pakistan and the Philippines to buy kidneys from vendors and intermediaries. These organised organ sales were facilitated by doctors, hospitals and even travel agents, and sometimes by governments. In Iran, kidney sale was regulated by the government, and vendors were paid officially in order to satisfy the need for kidneys.

In China, executed prisoners became the source of multiple organs, such as heart, liver, and kidneys, against international regulations which do not consider prisoners sentenced to death in a position to give consent for organ donation. Many, if not most, of these organs were sold to wealthy patients from the Middle East, South East Asia, and Europe (5).

Declaration of Istanbul and WHO guidelines

In response to the spread of these unethical practices, the need arose for an international move, which was spearheaded by The Transplantation Society with support from the International Society of Nephrology and WHO.

Several meetings were held in different countries which culminated in a large meeting held in Istanbul in 2008. In this

meeting, 152 participants from 78 countries agreed on a set of principles opposing organ trafficking, transplant tourism, and commercialism.

The Declaration of Istanbul (DoI) (6) was soon endorsed by the majority of transplant and nephrology organisations around the world. A custodian group (Declaration of Istanbul Custodian Group, DICG) was formed to follow up the implementation of DoI around the world. Since the declaration, new laws and regulations came into effect aiming at putting an end to transplant tourism with success stories in many countries (7).

In addition, WHO introduced a set of guiding principles on organ transplantation outlining an ethical and acceptable framework for transplantation of human organs. These principles were endorsed by the sixty-third World Health Assembly in May 2010, in Resolution WHA 63.22 (8).

Both DoI and WHO recommended maximising donation from the deceased as an alternative to organ trafficking and commercial transplantation (9).

Organ shortage in Asia

Although organ shortage is a global problem, it is worse in Asia. Data published by WHO's Global Observatory (1) indicate that in most Asian countries the number of organs transplanted per million population (pmp) is between 2.5 and 9.9 compared to over 50 in most European countries.

A good number of kidney transplants are performed in Asia (10) indicating that infrastructure for transplant services is available; but a majority of these kidneys come from living donors and only 5.6% from deceased donors, compared to 70% from the same source in Europe. When it comes to organs other than the kidney, the problem is even more obvious. On average, less than 1 liver transplant is performed pmp in Asia (83% from living donors) compared to 9.5 in Europe (1). Heart transplantation, which depends solely on deceased donation, is extremely rare in Asia.

These harsh realities indicate that the crucial issue is the shortage

of deceased donation in Asia. Many Asian countries lack deceased donor programmes and when available the number of donors is very small, ie in the range 0–4.9 pmp (1). In Europe, the range in most countries is 15–20 pmp and is over 25 in several countries (1). Bearing in mind that several transplants are performed from each deceased donor, the severe shortage of organs in Asia becomes obvious.

Several factors are responsible for the shortage of deceased donation in Asia, such as availability of resources and proper organisation but even countries with a high Human Development Index (HDI) such as Japan suffer from this shortage, indicating a cultural or religious problem. Of course, there is no shortage of potential deceased donors in hospitals but turning them into actual donors requires a donation culture which is presently lacking in most Asian countries.

Overcoming organ shortage to achieve self-sufficiency

Pressures exerted over the past six years since the DoI have failed to put an end to illegal transplantation in Asia, and many activities continue underground and will not cease unless enough organs are available for patients in need (11). The only way to fulfil the demand for organs is by expanding the use of deceased donors. Despite the obstacles this may be achieved by the following means:

1. Laws and regulations

Many Asian countries still lack adequate legislation to allow or expand deceased donation and to protect specialists involved in the process (12). Compulsory referral of all possible cases of brain death in hospitals and presumed consent law (when every deceased is considered to be a donor unless he objected during his lifetime) have been effective in many European countries and may increase donors in Asia.

2. Transparency and fair allocation of organs

The public in many Asian countries may have problems in trusting authorities especially when it comes to looking after seriously ill patients in hospitals, declaring brain death, and equal distribution

of organs. Hence, transparency and a fair organ allocation system are essential for a successful programme in order to gain public support especially in countries where public mistrust is common.

3. Adequate organisation and budget

Organ procurement is an important and demanding specialty, requiring special training of transplant coordinators and intensive care unit (ICU) staff on identification of possible donors, donor maintenance, family approach, and organ recovery. Many governments fail to realise the importance of organ procurement from the deceased, not only in saving and improving quality of life, but also in saving money spent on taking care of patients with end-stage organ failure. A budget needs to be allocated by the state for this purpose and to provide facilities such as adequate offices, means of transport, and communication.

4. Involving public media and religious authorities

Adverse media is devastating for any transplantation programme especially when they report illegal practices such as organ sale or publish stories on crimes committed to obtain organs. It affects public trust and people will be reluctant to donate organs to a corrupt system.

On the other hand, showing the public the humane aspect of transplantation and how organ donation can save the lives of children and adults will encourage people to support it. Religious leaders have great influence on public opinion in most Asian countries and their understanding and support is essential. Most religions encourage the saving of lives; but there is misunderstanding and divisions on the recognition of brain death (13).

5. Promoting donation in schools

The development of a donation culture needs to be implemented at a young age. Many countries have been promoting donation and transplantation in school curricula in order to develop such a culture, which is presently missing in many Asian countries.

6. Providing incentives and removing disincentives

Removing disincentives by reimbursing donors for any financial loss due to donation, such as wages lost due to sick leave after

donor operations and covering transport and accommodation costs are accepted by the DoI (4) but providing monetary incentives to donors is prohibited (14).

Some countries such as Kuwait and Saudi Arabia achieved good deceased donation rates by providing financial support to donor families in need. In both countries, there is a large expatriate population, most of whom are low-income workers and when they die, their families lose the little money they were receiving monthly and may not even be able to repatriate the body of their deceased to his home country. The governments in both countries cover the costs of repatriation and also provide the family with some financial support to help them manage for a while before finding an alternative source of income. The organs generated are distributed free of charge to patients on the waiting lists.

The proponents of such a system argue that this is different from inducing a living donor as the person is dead and you are providing support to a devastated family at a time of great need (15). Religious authorities also support this solidarity with poor donor families, although they object to inducing living donors.

However, this cash payment is debatable and contradicts the principles of the DoI and WHO. Offering fixed cash payment is considered as an unacceptable pressure on poor families to give consent, when many of them might refuse if the reward were not offered. Such an offer can be considered as coercion similar to coercing a living person to donate an organ for money.

This model can be modified to provide humanitarian support to donor families, if needed, within an ethically acceptable framework, not including fixed cash payments. This could be done in the form of educational grants provided to the deceased's children to continue their education, or providing a long-term interest-free loan to allow the family to start a small business to sustain itself. This support can be provided and managed by charities.

Success stories

Achieving self-sufficiency in transplantation in Asia is certainly not easy, but there are countries that are moving fast towards this. A good example is Iran (16), a populated country with the same cultural, religious and socioeconomic background as many other Asian countries. There was hardly any deceased donation before the year 2000. After passing a law recognising brain death, and allowing organ procurement from the deceased, the rate of deceased organ donors jumped from less than 0.2 to over 10 pmp in 13 years and the rate is still rising (2).

The transplant programme in Namazi hospital in Shiraz, Iran, is a reflection of this success. With over 350 liver transplants every year (86% from deceased donors), it has become the largest liver transplant programme in the world. Since 2008, 92% of kidneys transplanted have been from deceased donors, the rest being from living related donors. The programme is based on altruistic donation (17). The programme achieved this by excellent organisation of organ procurement units, especially in Tehran, and support from the government, media, and religious leaders. The incentives provided to donor families are non-financial. The families of the deceased donors are honoured by the media and authorities, and the body of the donor is buried in a martyr's graveyard, considered a great honour in Iran. As a gesture of appreciation, families also receive priority in accessing health services.

This efficient model could work well in Asia and be effective in abolishing the black market for organs by providing life-saving organs for patients in need (18).

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Deceased organ donation in India: Where do we go from here?

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Abstract

Transplantation represents one of the best examples of the scientific achievements of medical science. However, its success has also led to some of the fiercest ethical challenges in modern medicine. Partly as a response to the uncovering of a flourishing clandestine kidney trade, the Central government promulgated the Human Organs Transplant Act (HOTA) in 1994. HOTA, along with its amendments, was a step forward in recognising concepts such as brain death. Nevertheless, there are numerous ethical challenges still to be resolved, particularly with regard to consent, incentives to donors and families, and equitable distribution of donated organs.

Introduction

Transplantation represents one of the best examples of the scientific achievements of medical science. However, its success has also led to some of the fiercest ethical challenges in modern medicine. The number of patients desperately needing a transplant far outnumbers the available organs, leading to a competition for organs which severely tests the principles of transparency and distributive justice. Transplantation is also unique in that it needs public sanction without which it will collapse. Although living donation is an option for some organs, the main source of organs is deceased donation which hinges on consent from family members. This consent is shaped not only by the perceived credibility of the process but also by other cultural, religious and political factors. On the recipient side, the ethical challenge is how to ensure justice

in allocating the few available organs to someone from amongst a large pool of patients on a waiting list.

The discourse surrounding organ transplantation covers a wide sweep of disciplines like sociology, anthropology, culture studies, public health, economics and politics. Central to the discussion, however, is ethics. Over the years this discipline has engaged with these debates in an intense and rigorous manner. Since its inception the pages of this journal have carried a wide variety of writings on this topic, about its global overarching dimensions as well as the Indian context. South Asia in general, and India in particular, has had to grapple with the specific issue of the enticement of the desperately poor to sell their organ for a price (1). The recent increase in cadaveric or deceased donation in India has been acclaimed by many in the lay media. In certain states it has also been argued that this has led to a reduction in commercial transplantation (2). But there has been a paucity of the social and ethical analysis necessary in a field where so much is at stake.

Organ transplantation in India has a relatively short history compared to the developed world. India's conceptual and scientific contribution to this specialty has been limited even as it has been at the epicentre of one of the biggest ethical controversies concerning transplantation. Kidney transplants in India were first performed in the 1970s. Though transplant activity picked up in the 80s and early 90s, it was largely restricted to live donor kidney transplants in selected urban centres. In the 1990s the establishment of more centres and the availability of trained staff, led to an increase in kidney transplants. Transplantation of other organs such as the liver is a very recent activity.

It is pertinent to note at the outset that the benefits of transplantation are still not available to a large proportion of India's population needing them. Many patients with end stage renal disease are on long-term dialysis and lead a very poor quality of life. Even dialysis facilities are limited, expensive and inaccessible. More than 90% of patients in South Asia die within months of diagnosis because they cannot afford treatment (3). It has been estimated that only 2.5% of patients with end stage renal disease in India actually end

up getting a transplant (3). For the liver, this proportion would be an even more miniscule minority. There has been little substantial activity in transplantation of other organs like the heart and lungs.

The kidney trade in India

Organ transplantation in India has received prominent coverage in the media, one major reason being the notorious kidney trade in the 1980s. Foreign patients flocked to India for transplants from paid “donors”. These transplants were often performed clandestinely in small hospitals in substandard conditions, but some large private institutions tacitly participated in this activity. The results of these transplants were also poor (4). While the media reported on these scandals, medical bodies, including medical councils and other regulatory bodies, largely remained silent. This was not surprising considering that self-regulation of medical practice in India has historically been very weak. Also, the kidney trade earned huge monetary benefits for the rapidly expanding private sector. A significant section of the medical fraternity, including nephrologists and kidney transplant surgeons, was complicit in the kidney trade.

Attempts were made to offer an ideological rationale for this activity, seeking to justify paid-for donations as consistent with a libertarian and free market philosophy (5). Using the same logic, there were calls for a “regulated” market. It was, however, obvious on the ground level that the donors in this market had often been coerced and even been duped by middlemen of any monetary rewards. Also, follow-up studies of unrelated donors showed that their quality of life was poor (6). Countries like Iran have experimented with a state-sponsored regulated model and claimed some success (7). While the details of this debate do not belong in this paper, it is important to keep this bit of history in mind when addressing issues related to deceased donation.

The Transplantation of Human Organs Act

Partly as a response to the kidney scams, the Central government in 1991 constituted a committee to prepare a report which could form a basis for all-India legislation governing organ transplantation. Although the main terms of reference of the committee were

concerned with “brain death”, it also recommended that trading in human organs be made a punishable offense. In 1994, the government of India promulgated the Transplantation of Human Organs Act (THOA) (8). The Transplantation of Human Organs Rules followed in 1995. Subsequently the Rules alone were amended in 2008. Later, THOA itself was amended in 2011. The Rules for the amended Act have just been notified, in 2014. THOA of 1994 banned any form of “commercial trading” in organs. Unrelated donation was permitted on grounds of altruism but only with the sanction of an authorisation committee. The committee took a decision on the basis of documentation and interviews of both prospective donor and recipient.

Even after the promulgation of THOA, scandals involving unrelated donors continued to break out in the media. In the last few years there seems to have been a decrease in media exposes. This may reflect an overall reduction in what was once a thriving industry, but it is also believed that some of the activity has moved underground, and some has moved out of the country where the wealthy and influential have taken advantage of the apparently liberal laws in countries like Singapore and undergone live unrelated transplantation there (9).

Simultaneously, THOA also legalised brain death in India, paving the way for performing deceased donation by procuring organs from brain stem dead donors. The Act also laid down criteria for determining brain death. Safeguards against misuse were built into the rules. The tests for brain death had to be performed together by four individuals, none of whom had anything to do with the transplant. The tests were to be done twice, with a minimum gap of six hours. As per the law, brain death could be declared only in institutions recognised by the state appropriate authority. Written consent for donation of organs from the deceased person had to be obtained only from a close relative. The law and most of the scientific criteria and the methodology of diagnosing brain death were essentially derived from the British law.

Problematic interpretations of the law

The law seemed to define brain death only in the context of organ transplantation, setting the stage for a peculiar situation. A disquieting and widely prevalent interpretation of the law by the medical community in India is that if brain death is diagnosed and the family refuses consent for donation, there is no legal sanction for disconnecting life support, including the ventilator. This has led to a major ethical predicament on the ground. The family is informed that their relative is “dead” and asked for consent for donation. But if they refuse and request that the body be handed over, their request to withdraw life support is turned down.

The law also identified only hospitals performing the transplant operation as recognised institutions where brain death could be declared. Thus in the large number of institutions where transplantation is not being performed, declaration of brain death was not possible. This led to bizarre situations where the cadaver donor had to be shifted to another recognised institution only for the purpose of organ retrieval. A recent amendment of the Act in 2011, and of the Rules in 2014, have created a category of institutions called “non-transplant organ retrieval centres” where organs can be retrieved after consent and then transported to an institution where the recipient procedure is to be performed. However, a large number of institutions are still not recognised and prospective donors are often transferred to transplant recognised hospitals. This is an obvious conflict of interest scenario as the hospital can then use the organs as it gets priority as an “in house” donor. There is, therefore, the possibility of inducement to transfer potentially brain dead individuals with even “soft” incentives like fee waivers.

The question of whether brain death can be declared independent of organ donation is still an open question. In reality, brain dead individuals are still hooked on to intensive organ support measures (10). In a country where intensive care unit beds and ventilators are scarce, this often means denial of care to another patient with a serious illness.

For a long period after the Act was passed in 1994, there was little substantial activity in terms of declaration of brain death

and donation after brain death. As of 2014, some 2,500 cadaver transplants have been performed in India, mainly in the last five years in the states of Tamil Nadu, Andhra Pradesh, Maharashtra, Kerala and Gujarat. Tamil Nadu, and the city of Chennai in particular, has seen significant success in cadaver donation with around 1,400 cadaver organs transplanted till date (11). Tamil Nadu's relative success has been ascribed to multiple reasons, including frequent interaction between the government and stakeholders, and provision of the necessary legal and administrative back-up through regular government orders facilitating the process. The Tamil Nadu programme has also attempted to maintain absolute transparency from its inception. Mumbai has witnessed an increased in cadaver donations in the last few years (12) and has already seen 15 donations in the first six months of 2014.

A closer look at donation patterns across the country reveals that deceased donation is largely driven by hospitals with active transplant programmes. These institutions directly benefit, monetarily or otherwise, from identifying brain death and promoting donation. These institutions are largely in the metros and often in the corporate sector.

Ground realities in India

Problems peculiar to the Indian situation have come up in the practice of deceased donor transplantation. The diagnosis of brain death and subsequent donation is possible only in intensive care units (ICUs) which have the facilities for keeping a brain dead patient's organs working with mechanical ventilation, cardiac support and intensive monitoring. Such ICUs are few and are available only in big hospitals in major cities. They are often overloaded and understaffed and lack a central command structure. In this situation, the identification of brain death and requesting consent is often given low priority and brain dead patients are treated with "benign neglect". But if such patients become donors, they require the same attention as any other patient to keep the organs viable till they are removed. This requires a major attitudinal change and is resented by an already overburdened staff.

Another conflict inevitable in this resource-constrained scenario concerns where to use inadequate resources: on sick patients who need life-saving care to save their lives or on care of the brain dead potential donor. Since most donors are in the private sector, the cost of their maintenance has also been an issue. How does one bill a family which has donated organs? And as common sense dictates, if the bill should be waived, from what point in the illness should it be done? And will waiving of the entire bill in the private sector be seen as inducement?

In the early years of deceased donation in India it was thought that cultural, religious and social beliefs, and lack of public awareness, prevented families from giving consent. The lack of progress in cadaver donation was often ascribed to lack of public awareness. However, it was soon obvious that there were other factors impeding donation and that the consent rate would go up significantly if institutions made systematic efforts to identify and approach family members of brain dead donors, the consent rate was likely to be significant. Cadaveric transplants were not being performed, not because of lack of awareness and refusal by families to donate, but because of absence of institutional mechanisms to approach the families of brain dead individuals. It has been the same story as in eye and blood donation, which has a much longer history in India.

Across the world, the form and method of obtaining consent for removal of organs from brain dead individuals has evolved over the years. The most common is "informed consent" in which close family members agree to donate organs after brain death has been certified. This is the form of consent that has been practised in India. However, "family consent" is a vague term, and, unlike in some countries, no hierarchy of relatives has been specified in the rules. There have been cases of differing views within the donor family. The ethical question here is: whether unanimity in concurrence is to be sought, and if not, whether one family member's views can override others.

Other forms of consent

In the rest of the world, in an effort to increase the donor pool, other strategies are now being debated and implemented. The first area involves improving the consent rate for brain dead donors. This includes “donor cards” which citizens sign and keep during their lifetimes; “required request” where it is mandatory for a doctor to ask the relatives of a brain dead patient about organ donation, and, in some countries, “presumed consent” which grants authority to doctors to remove organs from brain dead individuals whenever usable organs are available, in the absence of objection from the deceased in his or her lifetime, or from the family members. Financial and other incentives to families of deceased donors have also been debated as an option.

Such strategies have also been proposed and debated in the public domain in India. The recent modification of THOA rules in 2014 seems to propose a “required request” strategy which makes it mandatory for the ICU doctor to identify brain death and ask the relatives of the brain dead patient about organ donation. Such a strategy is debatable in the heterogeneous, unregulated and unstructured healthcare scenario in India. This partly coercive and top down approach is likely to lead to tensions and resistance from a medical fraternity unprepared for this paradigm shift. The actual impact of such strategies remains to be seen, but they have not been adequately debated in the public domain.

In some European countries, such as Austria, Belgium, Denmark, Finland and France, “presumed consent” has been legalised and is practised. This grants authority to doctors to remove organs from brain dead individuals whenever usable organs are available, in the absence of any objection from the deceased in his or her lifetime, or from family members. Presumed consent places the burden of opting out of organ donation on those who object to this procedure. This form of consent was introduced in these countries after a long history of cadaveric donation as well as public debate on the issue. The introduction of such a strategy is occasionally debated in the public domain in India as a knee jerk reaction to the poor progress in deceased donation (13). Such constructs have their origin in a developed and structured western Anglo Saxon

society and need in-depth debate and discussion before being considered here. One shudders to think of the Pandora's box that such legislation would open in this completely unregulated healthcare system. The argument that individuals after their death should serve "the greater common good" brings up many questions (13). For one, what constitutes the "greater common good"? Can we, for example, use the common good argument to legislate to stop people in large cities using automobiles and instead use public transport to reduce pollution, which is a major silent killer?

Donation after cardiac death

In an earlier issue of this journal, Bardale (14) discussed the relevance of an alternative form of cadaveric donor, the "non heart beating donor" (NHBD), otherwise called "donation after cardiac death". As opposed to the brain dead donor, whose brain is irreversibly damaged but whose heart is beating and circulation is intact, the heart of the NHBD has ceased to beat and circulation has ceased. In the NHBD the organs need to be removed instantly for them to be viable for transplantation. In the mid-1990s there was a resurgence of interest, and acceptance, in the West in using organs from NHBDs. In 1995 the Maastricht classification of NHBDs was put forward (15). However, the wider application of NHBD has brought up a number of complex ethical dilemmas, dealing essentially with the end of life.

The implementation of such programmes in a scenario such as India's will need both social and cultural acceptance, and substantive regulatory mechanisms (16). It will also need the presence of trained medical teams who can conduct almost instantaneous removal of organs in a planned manner. But there is no reason to believe that families who would consent to organ donation after brain death would not do so after cardiac arrest. In fact, it is easier to understand and accept the concept of cardiac death. The scientific and legal base for it has been prepared in the rest of the world. This could be an area for India to explore in an effort to increase the donor pool.

Incentives for deceased donation

There has been much discussion in the recent transplant ethics discourse on offering some form of incentive to families of deceased donors (17). This is being tested in countries like China (18), and there have been calls by Western ethicists to consider limited incentives like payment of funeral expenses (17) to donor families. This has not as yet entered the realm of policy.

The idea of incentivising donor families has also been discussed in the public domain and transplant circles in India. The incentives discussed range from simple waivers of the donor's hospitalisation costs to various proposals to support the donor's family members, including preference in jobs, free lifelong railway passes, and support for children's education. Since the recipient and the hospital performing the transplant are beneficiaries of the donation, it has been argued that there is no reason why the act should not be acknowledged and compensated in some form. This idea may seem to have some merit, especially since the recipient is often a rich person. However, any form of compensation inevitably commodifies the act of donation. Also, in an intrinsically unequal society this could be the slippery slope to inducement and a soft form of trading even in deceased donation. The inevitable scandals and intrigue surrounding this will impact the small but significant altruistic cadaveric donation programme which is just taking off in major cities.

Who is getting the organs? Addressing inequity in the recipient pool

The current allocation policies for deceased donor organs differ from state to state within India. There is no unanimity on whether the organs should be allocated based on severity of disease, waiting period or on an institutional rotation. There is an attempt to centralise the activity by the formation of a National Organ and Tissue Transplant Organisation (NOTTO) under the Ministry of Health and Family Welfare. One of the stated objectives of this organisation is to evolve a national network for organ sharing. However, given that India is a large and diverse country with regional variations and aspirations, a very centralised approach

may not be appropriate, and the states must be allowed flexibility in approach as long as they meet basic ethical requirements.

THOA laid down elaborate criteria on who can donate organs, but did not elaborate on how the donated organs would be distributed. Conceptually, donated organs do not belong to the hospital or the city where the donor's death took place; all altruistic donations belong to society as a whole. Thus the state has a responsibility to ensure that such organs are distributed in a transparent and equitable manner to those who need them, and not to those who can afford them. If they leave the decision to market forces, the state and the transplant community are breaching the trust placed in them by donor families.

Healthcare in India is dominated by the private sector. This domination is even starker in organ transplantation. Transplant programmes in public hospitals are restricted to a few large teaching hospitals in the metros. Even these are overburdened and often in disarray. Even a fairly standardised and straightforward procedure like kidney transplantation is performed in very small numbers in the public sector. For example, none of the Maharashtra government's large teaching hospitals currently conducts kidney transplants. I estimate that less than 1% of the liver transplants performed in India have been in the public sector. Partly because of the poor progress in deceased donation, a large proportion of these are living donor transplants. The rapid proliferation of live donor transplants has been accompanied by a worrying number of donor deaths in this complex procedure which involves a significant risk for the donor (19). The pressure for a transplant is much more since, unlike the kidney where there is a backup of dialysis, patients with end stage liver disease have no such option.

Transplantation is complex and costly and there is almost no state funding for this procedure. Most of the activity in deceased donation has been in the private sector. In addition, a significant number of donors and a large majority of recipients are from private hospitals. Any call for altruism from the public is undermined by the fact the large majority of the organs currently go to the rich. It is imperative for the state to remove this incongruity and make transplantation accessible and affordable to all, regardless of their

ability to pay. This will need political will and the mechanisms to build in social equity into the current distribution systems. One method of doing this could be to mandatorily allocate a proportion of organs for public sector institutions. Of course, this will have to go along with development of transplant facilities in this sector, something that is currently severely lacking.

In its present form, cadaveric donation in India largely benefits the rich and serves a miniscule percentage of the patients who need it. Thus, whilst we must continuously strive towards increasing donation rates we must not lose sight of this big picture. Many of the ideas and concepts in modern deceased donor transplantation come from the developed West where both societal attitudes and health systems are different from those in India. We in India need to develop a system which is equitable and transparent and not coercive. This will be a slow and difficult process that may also require linking to the bigger struggle for an advanced and yet affordable healthcare system for all.

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After presumed consent: a review of organ donation in Singapore

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Introduction: three schemes of organ donation

Singapore was the first Commonwealth country to enact, in 1987, a presumed consent law for organ donation (1). Referred to as the Human Organ Transplant Act (HOTA), it applied only to persons between the ages of 21 and 60 years who had suffered accidental deaths certified by the criteria of brain death or cardiac death; who were non-Muslims; and who had not formally dissented from (“opted out of”) organ donation. The actual policy was implemented in 1988, after a six-month period to allow objectors to register their dissent, and applied only to donation of kidneys. The new law at that time came into existence alongside the older Medical (Therapy, Education and Research) Act (MTERA) of 1972, an “opt-in” scheme of voluntary donation, where persons could pledge to donate their organs and tissues (eg kidney, liver, heart, cornea, lung, bone, skin, heart valves, etc) for the purposes of transplantation, education or research upon death. An amendment to the HOTA in 2004 also permitted living organ donation, and permitted retrieval of other types of organs besides kidneys (livers, hearts, and corneas). The 2004 amendment further included all causes of death rather than solely death by accidental causes. Hence, in effect, three schemes of organ donation were set in place in Singapore by 2004, and further legislative amendments (2007, 2009 to HOTA) were made with the firm intent of expanding the supply of transplantable organs, and ensuring that organ donors are not exploited, unlawfully induced, or forced into organ retrieval by others (see Table 1).

The current provisions for organ donation by voluntary donation, presumed consent and living donation in Singapore are explained

Table 1 :
Legal provisions to expand organ supply and curb donor exploitation in Singapore

Legislation and year	Provision	Remarks
MTERA (1972)	Persons have the legal right to donate parts of their body to approved hospitals, medical or dental schools, colleges or universities for "medical or dental education, research, advancement of medical or dental science, therapy or transplantation" or to "any specified individual for therapy or transplantation needed by him".	These legislative changes were undertaken gradually over time with intent
HOTA (1987)	Under a new opt-out system, individuals are presumed to have consented to organ donation upon death. Family members have no legal right of objection, although in practice, organ retrieval is carried out with due regard to families.	to both expand the supply of transplantable organs, and to ensure that organ donors are not exploited, unlawfully induced or forced into organ retrieval by others.
HOTA Amendment (2004)	Excluded Muslims, who were automatically considered objectors because under the Muslim Council's interpretation, removal of organs at death constitutes desecration of the deceased, and the consent of waris (paternal next-of-kin) was necessary for organ donation. Muslims in Singapore could opt-in to organ donation under HOTA, or pledge their organs under MTERA. Muslim exemption from presumed consent was removed in 2007, following a religious ruling by the Islamic Religious Council of Singapore permitting Muslims to come under the HOTA. The Act was amended to permit retrieval of other types of organs besides kidneys (livers, hearts, and corneas), and all causes of death rather than only death by accidental causes.	
	Living donor transplants were legalised, but written authorisation by a hospital ethics committee was required and applicants had to be screened for eligibility.	
HOTA Amendment (2009)	The Act was amended to remove the upper age limit of 60 years for deceased donations to allow transplantable organs to be assessed for medical suitability.	
	Paired exchanges permitted.	
	Reimbursement of donors for documentable or reasonable costs allowed. Under Section 14 (3)(c) of the HOTA, costs that may be reimbursed include expenses incurred for medical procedures, childcare, loss of earnings, short- or long-term medical care as a consequence of organ donation.	
	Regulatory oversight of all living organ donations was established under Section 15A (3) through appointment of doctors and laypersons to a National Panel of Transplant Ethics Committees (hereafter TECs).	
	Organ commercialism outlawed, with heavy penalties instituted including hefty fines (up to SG\$100,000) or a jail term (up to 10 years), or both.	

Table 2 : Legislative provisions for organ donation in Singapore			
Act	HOTA		MTERA
Source	Living	Cadaveric	
Consent	Voluntary	Presumed consent	Voluntary
Age			Age limit for organ pledging: 18 years and above The adult next-of-kin can also pledge the organs of deceased patients of any age for donation.
Organs included	Kidney Liver	Heart Cornea	All organs and tissues
Purpose(s)	Transplant		Transplant and treatment Education Research
Nationality	Singapore citizens and permanent residents		Any nationality
Religion	Any religion (Muslims included under HOTA from 1 August 2008)		Any religion (For Muslims, MUIS has issued <i>fatwas</i> stating that the donation of kidney, liver, heart and cornea is permissible.)

in Table 2, based on current information on the Ministry of Health’s website (2).

The current situation

Organ donation rates under Singapore’s older opt-in law (the MTERA, enacted in 1972) have been poor despite door-to-door canvassing and media publicity throughout the 1970s and 1980s, and continuing transplant awareness education through information booklets posted to citizens and permanent residents six months before the age of 21. Even after 35 years of canvassing donors for pledges, only 1.3% of citizens and permanent residents pledged their organs in 2007 (3).

These low take-up rates had prompted the introduction of the presumed consent/opt-out system under the HOTA in 1987. Opt-

Table 3 :

Improving the organ donation experience: proposals from the literature

Reasons for low procurement among stakeholders

Proposals*Individuals*

1. Fear of death or apathy lead to individual failure to pledge organs, or express preferences about organ donation

2. Fear of surgical risks and risks to health and employment

3. Mistrust of medical professionals

1. A presumed consent system addresses this preference for silence; but the voluntary communitarian basis of this system must be well-publicised and accepted within society.

2. Investments in trained transplant coordinators, and dissemination of trustworthy information on organ donation risks should be undertaken by hospitals providing transplant services.

3. Transparent guidelines and protocols for hospital intensivists regarding withholding/withdrawing mechanical supports, evaluation of brain death, and donor identification should be developed.

Professionals

4. Uncertainty about the ethics of, and protocols for, determining brain death

5. Uncertainty about the ethics of, and protocols for, communication with families about organ donation after brain death

6. Uncertainty about the ethics of, and protocols for, donation after cardiac death

4. Intensive care protocols should be independently carried out regardless of a patient's organ donor status or suitability.

5. Organ donor suitability should be evaluated by transplant coordinators, and discussed with the patient's family, only after decisions to limit life-sustaining treatment have been independently taken, or a determination of brain death has been independently carried out.

6. Once decisions to limit life-sustaining treatment have been independently taken, transparent and well-validated protocols for commencing organ preservation procedures and treatments should be explained to families. The ethical basis of donation after cardiac death is the presumed consent of patients who have not opted out of organ donation. The ethical basis of commencing organ preservation procedures and treatments must lie in reasonable professional certainty that these are not harmful to the patient. Its legal basis is provided under the HOTA.

Families

- | | |
|---|---|
| 7. Bereavement | 7. Transplant teams should be sensitive to the needs of family members in bereavement, and should develop protocols (such as time-limited stays on organ retrieval) that reflect consideration towards families. Skilled counsellors should help families to potentially seek solace in the beneficent act of organ donation. |
| 8. Cultural and religious beliefs | 8. Transplant coordinators should be careful not to rely on stereotypes and assumptions about religious and cultural traditions, and how individuals bring such considerations into organ donation and other decisions. |
| 9. Uncertainty about the patient's wishes | 9. Transplant coordinators should be mindful that family members who have no prior knowledge of a deceased loved one's wishes may also rely unduly on stereotypes and assumptions, and should be prepared to engage in more considered discussions about known aspects of the patient's character and general values and preferences. |
| 10. Family conflict (living donation) | 10. Family relations can be disrupted by an organ donor's decisions; but families can sometimes also exert undue pressure on donors. Transplant teams should deal carefully with such situations, and in helping donors to come to an informed choice, consider the extent to which an organ donation decision strengthens or harms a patient's critical interests. |

outs are rare, and this observation is consistent with research conducted regarding defaults and organ donations. Results of the survey revealed donation rates to be double in an opt-out system as opposed to an opt-in system (4). Between 2004 and 2009, only 2%–3% of Singaporeans opted out of donating organs after death (3). Hence, the presumed consent law had effectively increased the donor pool by more than 95% of the Singapore population. Yet, donor actualisation rates continue to fall. The introduction of the HOTA increased the rate of deceased donor kidney transplants from 4.7 per year during 1970–1988 to 41.4 per year during 1988–2004 (5). But early expectations of increased organ retrieval over time through the presumed consent to donation scheme enacted in

the HOTA have not materialised (5, 6, 8). For example, in spite of legislative efforts, the number of renal failure patients getting transplants through cadaveric and living donors has fallen over the years from a peak of 124 in 2004 to 62 in 2012;¹ this has been attributed to a dearth of deceased donor pledges and willing living donors (9).

With the initial enthusiasm about the presumed consent system, some members of the transplant community claimed that, while Singapore's religious and cultural pluralism might present many obstacles to deceased organ donation, social changes were afoot that would render obsolete, or at least ameliorate the effects of, belief systems that opposed the retrieval of bodily organs after death (10). However, while social change may be the reason that recent findings regarding the positive attitudes towards living organ donation of Singaporeans who are younger, more educated, have higher incomes, are single (never married, divorced or widowed), and hold professional jobs (11), this change alone has not reversed organ procurement rates in Singapore over time.

There have been repeated calls by transplant physicians in Singapore for better public education on ethical, cultural, and religious aspects of organ donation (1), improving physician training in the logistics of actualising donor referrals (3), in tandem with preventive measures to stem the tide of organ failure from rising rates of diabetes in Singapore's ageing population (12). In the case of kidneys, the donation rate has been consistently low by international standards. In 2004, although the number of kidneys transplanted through retrieval from deceased and living donors reached a peak, the donation rate for cadaver kidneys remained low in Singapore at 8 donors per million population (pmp) compared to between 13 and 34 pmp in Europe (13).

Reasons for low organ procurement rates

The reasons for low organ procurement rates from cadaveric and living sources in Singapore are also well-documented. Transplant teams report several clinical and ethical challenges in donor identification, donor referrals, and donor actualisation (3).

1. Organ pledges are rare due to many personal factors including, according to physician reports, apathy and inertia, fear of

death and reluctance to discuss death, belief that medical decisions to withhold or withdraw life-sustaining treatments would be influenced by one's donor status, and feelings of personal uncertainty about transferring organs into the bodies of strangers (10).

2. The concept of brain death remains an ethically ambivalent issue, and closely tied to the need to clarify the conditions under which organs may be legitimately retrieved from the deceased for transplantation (13). The 'dead donor rule' which has fuelled widespread professional discomfiture in modern healthcare is no less controversial in Singapore (14).
3. Continued reliance on identifying potential donors from brain dead heart-beating patients only, and leaving out the much larger numbers who could be identified for donation after cardiac death on the presumption that the organs retrieved from this source are of poorer quality (3). At the same time, protocols for instituting organ preservation techniques and controlled cardiac death are still regarded as controversial (15).
4. Continued reluctance to deploy extended criteria for donation, such as organs from deceased donors with clinical risk factors, on the assumption of poorer outcomes compared to transplantation using organs that meet the standard criteria (16).
5. When grieving family members object to organ retrieval by presumed consent to donation, in the face of uncertainty about the wishes of the deceased, doctors have been reluctant to press the issue (12).

This consideration of familial bereavement, however, differs from the process of informed consent, which, as part of HOTA, happens at the age of 21 when the person receives a packet with information on the Act and necessary forms for opting-out. Persons who do not register an objection to removal of organs under the HOTA are presumed to have consented to organ donation on an informed basis. Families although lacking a legal right to stop the retrieval of organs, are appropriately given due concern for their bereavement. The doctor's reluctance to press the issue can be better managed as mentioned in point 7 under proposals in Table 3.

1. Some insight into the dearth of living donors has been provided by researchers who have investigated family members' reasons for not donating. Besides the fear of the risks of surgery, risks to health and other individual factors (11), family pressures weigh on the organ donation decision for both potential donor and potential recipient. Such decisions can be so pressurising on families as to sever long-standing ties when potential donors keep silent or disappear, and potential recipients feel abandoned or betrayed (10). Sometimes, objections are raised by in-laws and other relatives (1).
2. A report on Chinese traditional cultural beliefs surrounding organ donation predicts that family consent to donation of a loved one's organs after death would be rare among the Chinese, who constitute 74.2% of Singapore citizens and permanent residents (17). Proper disposition of corpses in accordance with Confucian beliefs about filial piety, popular beliefs about spiritual presence in bodies for several hours post-death, fears about angering the ghost of someone whose body is subjected to organ donation or autopsy, fears of offending the "angry ghosts" of persons whose lives were ended in an untimely manner by accidents, homicides, suicides, executions, etc (18).

Table 3 summarises the reasons for low organ procurement rates in Singapore, as reported in the literature, and ethical and practical issues to be addressed among stakeholders in future efforts to improve donation rates.

Conclusion

The history of organ transplantation in Singapore and the procurement of organs for transplantation are ethically sensitive issues. This review has focused on low organ procurement rates in Singapore over the years, and on the analysis of reasons that has become available in the literature on this subject. Writers have been equally prolific in recommending strategies for improving the organ donation record in Singapore, and expressing perspectives on the ethics of different approaches (1, 3, 16).

While the enactment of a presumed consent law in 1987 was momentous and led many in the transplant community to think that

progress in transplantation was inevitable, the reality as we now know has been less encouraging. The present consensus appears to be that legislation alone is not enough to raise organ donation to higher levels to meet the needs of patients with end-stage organ failure, a problem that has reached unprecedented levels in Singapore. Transplant professionals have pressed for better practical strategies to address the areas of personal motivation of donors, eg the willingness of younger Singaporeans to make living donations to intimates but not strangers, and the willingness of the elderly to donate to strangers (1!); the changes in cultural and religious beliefs in an increasingly literate population; investing in physician training to improve donor identification, referral, and actualisation rates in all hospitals (3); improving the organ donation experience for patients by enhancing trust in medical professionals and addressing misplaced fears concerning the medical risks of donation.

After presumed consent, the next era of transplant services in Singapore is likely to focus on ethically informed transplant practices that emphasise motivational factors in voluntary deceased and living organ donation; strengthening understanding of the present communitarian basis of the organ donation system under the HOTA; professional training, independence and integrity in the clinical and administrative setting in light of ethical objections to the “dead donor rule”, and the application of difficult-to-accept neurological criteria for the determination of death; judicious extension of donor criteria (donation after cardiac death, deceased donors with clinical risk factors) without compromising fair outcomes for all recipients.

Note:

- ¹ Another source places the figure at an even lower number of 51 kidney transplants in 2012. Available from: http://www.straitstimes.com/sites/straitstimes.com/files/20130811/ST_20130811_RBLIVER11A_3786808.pdf

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Organ donation in the Philippines: Should the dead do more?

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Abstract

This paper asks whether the Philippines should focus on ways of dealing with end-stage renal disease by getting more transplantable kidneys from the dead. Would it be more ethical to put the burden to donate on the dead (who have already lost their chance to consent) than on the living (who can consent)? Given the risks involved in undergoing nephrectomy and the lack of benefits arising from the procedure to donors, the dead should be the first to put their kidneys on the line. In the Philippines, unfortunately, living donors have had to bear the greater burden in this regard. Starting with a brief account of developments surrounding the impact of the Declaration of Istanbul on the situation in the Philippines as well as in other countries, the paper examines what the living have been expected to do, what they have actually done, and what lessons the experience with living donors offers for the understanding of cadaver transplants. The paper then looks at possible ways of increasing the sources of kidneys for transplantation and asks if these ways could be implemented successfully and ethically in the Philippines.

Introduction

Organ transplantation is a medical intervention whose success for a patient is primarily dependent on what another person, living or dead, and who is not part of the medical team, can contribute. A number of organs can be transplanted but for the purposes of this paper, the focus is on kidneys for transplantation in the context of the Philippines. This paper asks whether the dead should do more. Should the Philippines focus on ways of dealing with end-stage

renal disease by getting more transplantable kidneys from the dead? Would it be more ethical to put the burden to donate on the dead (who have already lost their chance to consent) than on the living (who can consent)? Given the risks involved in undergoing nephrectomy and the lack of benefits arising from the procedure to donors, the dead should be the first to put their kidneys on the line. Unfortunately, that does not seem to be the way things have happened in the Philippines. For a long time, living donors have put their kidneys and health and safety on the line for renal patients.

By way of a background, this paper starts with a brief account of developments surrounding the impact of the Declaration of Istanbul (DoI) on the situation in the Philippines as well as in other countries. It is pertinent to ask what the living have been expected to do, what they have actually done, and what lessons the experience with living donors offers for the understanding of cadaver transplants. The paper then proceeds to examine the situation as regards dead organ donation by looking at possible ways of increasing the sources of kidneys for transplantation. We ask if these ways could be implemented successfully and ethically in the Philippines.

Impact of the DoI

As a guidance document, the DoI on Organ Trafficking and Transplant Tourism has had a remarkable impact on the improvement of ethical organ transplantation throughout the world. Issued in 2008, the Declaration was adopted by the participants in the International Summit on Transplant Tourism and Organ Trafficking Convened by the Transplantation Society and the International Society of Nephrology in Istanbul, Turkey. Many medical societies and national government agencies have supported the implementation of the DoI since the time of its adoption.

Self-sufficiency is one of the principles that lie at the core of the DoI (1). This principle encourages countries to try to meet the needs of patients requiring transplantable organs internally and thereby limit, if not totally eliminate, cross-border transplantation

and transplant tourism. Other than simplifying the task of monitoring activities for national authorities, adherence to the principle of self-sufficiency also provides motivation to try to improve deceased donation rates, especially where the latter may be difficult to undertake because of a perception of incompatibility with local religious beliefs. Self-sufficiency is supposed to guide the Declaration of Istanbul Custodian Group (DICG) as it works in partnership with other concerned institutions to implement strategies intended to fight exploitation and ensure that the practice of organ transplantation leaves behind a legacy of celebrating a gift of health by one individual to another rather than a trail of impoverished victims of organ trafficking and transplant tourism (2).

After five years, the DoI appears to have achieved a lot in reducing organ trafficking and transplant tourism across national boundaries. International consensus against these practices has grown, which is reflected in governmental policies and responsive legislation in many countries. For example, the implementation of regulations prohibiting living donor transplants from Filipinos to non-Filipinos has resulted in a drastic reduction of transplant tourism to the Philippines (3, 4). Writing about progress made in various countries after the launch of the DoI, Danovitch and Al-Mousawi (2) have cited laws and regulations meant to curb organ trafficking in the Philippines, Colombia, Pakistan, India, Egypt, and Russia. In Israel, a new law on organ transplantation prohibits health insurance companies from reimbursing the medical expenses of patients who travel abroad to receive transplants, criminalises organ transplant brokering, and provides for full reimbursement of legitimate expenses associated with organ donation (5). Since the law was passed, the number of Israeli patients who travel abroad to purchase organs has dropped and living donation within the country has increased (6, 7).

Singapore has enacted a Human Organ Transplant Act (2012) (8) explicitly prohibiting payment for living donation. It has also set strict guidelines for reimbursement of legitimate expenses. In Qatar, the 2009 Doha Donation Accord has been touted to be an innovative model of a framework to promote

living and deceased donation in a developed country with a large expatriate population (9). Japan passed legislation in 2009 with provisions that could deal with its transplant waiting list without having to depend on external resources (10-12).

In order to discourage Malaysians from going abroad for transplants, the Malaysian Health Minister expressed support for the WHO Guiding Principles (13) and announced new legislation mandating the government to stop providing free immunosuppressant medications to patients who have commercial transplants performed abroad. The new law took effect in January 2012. It was meant to curb transplant tourism from Malaysia to China to take advantage of Chinese “donors”. More than 60% of the 1500 kidney transplants to Malaysians were performed in China from 2000 to 2010 (14). On the whole then, the promulgation of the DoI and the approval of the WHO Guiding Principles were followed by developments indicating progress in the global campaign against organ trafficking and transplant tourism.

The situation in the Philippines

Developments in the Philippines have followed the global trend to a significant extent. There has been an effort to contextualise transplant tourism and organ trafficking within the broader practice of human trafficking. Issued in 2009, Section 53 of “The Rules and Regulations Implementing the Anti-Trafficking in Persons Act of 2003” (15) expressly states that it is an act of trafficking in persons punishable by imprisonment of 20 years and a fine ranging from one million pesos (approx. US\$ 22,222.00) to two million pesos (US\$ 44,000.00) “to recruit, hire, adopt, transport, or abduct a person”, by means of threat or use of force, fraud, deceit, violence, coercion, or intimidation for the purpose of removal or sale of organs of said person. Thus, IRR9208 provided teeth to the prohibition contained in Administrative Order 2008-0004-A (AO 2008-0004-A) (16) by the Secretary of Health unequivocally declaring that “foreigners are not eligible to receive organs from Filipino living non-related donors.”

A total of 1046 kidney transplants in 2007 were listed in the Philippine Renal Registry, 2009 (17), compared to 690 in 2006.

The magnitude of the year on year increase indicates how fast the market in organs was growing during that period. Many patients were desperate enough to buy and many unemployed individuals were desperate enough to sell. Many hospitals and doctors were happy to play along as they also made a lot of money from the commercial transactions. More than 50% of the recipients in 2007 were foreigners and more than 80% of the donors were not related to the recipients (18). From 2002 to 2007, the number of living non-related donations increased from 157 to 844 whereas the number of donations from living relatives increased only slightly from 138 to 173. Cadaveric donations increased only from 10 to 29.

Transplants to foreigners during the same period increased from 40 to 528, whereas the number of transplants to Filipinos increased only from 256 to 510. Of the 510 Filipino patients who received transplants in 2007, 170 got their kidneys from living related donors, 27 from deceased donors and 313 from living non-related donors. A study of 131 kidney vendors between 1999 and 2007 found that “85.2%93.2% of vendors were unrelated in any way to the recipients....[and that] between 56.3% and 64.3% of the surveyed vendors indicated that their kidney buyers were of foreign descent” (19). It was obvious that the country had become a transplant tourism destination and foreign patients were coming to the country to be matched with living non-related donors. Up to that point, the burden of organ donation was clearly on the living and on those who were not even related by blood to those who needed transplantable organs.

Now that the government's ban has been implemented, transplants to foreigners have almost ground to a halt. Living unrelated transplants to foreigners fell to 3 in 2009, 2 in 2010 and 2 in 2011 (17, 20, 21). During the same period, kidney transplants to Filipino recipients decreased in number to 381 while the number of transplants from unrelated donors showed a decline from 313 to 147. It is worth noting that transplants from deceased donors rose only from 27 to 88 (21).

The numbers indicate that the burden of undertaking risks in organ donation lay more with non-relatives than with relatives.

Unfortunately, this observation could not be explained in terms of a growth of altruistic fervour among possible organ donors.

Deceased organ donation

The DoI emphasises the need to make up for a decrease in the number of organs available for transplants arising from a global effort to curb organ trafficking and transplant tourism by promoting deceased donor transplantation. In this regard, the DoI notes: “educational programs are useful in addressing the barriers, misconceptions, and mistrust that currently impede the development of sufficient deceased donor transplantation . . .” (1). It is useful, then, to examine some of the measures that have been under consideration to broaden the pool of deceased donor organs for transplant.

Bypass bereaved family consent for deceased organ donation

There are those who maintain the view that the living have a right to the organs of the dead. According to one argument, “it is immoral to require consent for cadaver organ donation [and that] no one has the right to say what should be done to their body after death” (22). Another argument says that “the benefits from cadaver transplants are so great, and the harms done in going against the wishes of those who object so comparatively small, that we should remove altogether the habit of seeking the consent of either the deceased or relatives [and therefore] provide for the automatic or mandatory availability of donor organs” (23). If these arguments were to be accepted, it would seem that the responsibility of authorities would be focused on finding the best way to collect transplantable organs, allocating them according to the fairest criteria, and transporting them as expeditiously as possible to be transplanted to matching recipients.

It is not this paper’s intention to take up the rational merits (or demerits) of the arguments for bypassing consent totally. However, it is useful to consider the possible impact of measures that may be based on these arguments. Experience in various countries has shown that it can be counterproductive to try to procure organs

from the dead without consent from relatives. There is no reason to suppose that experience in the Philippines will be any different. On the contrary, there is even greater reason to believe that resistance from families will be greater. In the country, families rather than individuals see themselves as the basic social units for making decisions (or for giving consent) relating to emergency healthcare matters. Organ donation comes under the category of emergencies. Organ procurement that bypasses family consent is likely to create enough controversy to guarantee its failure.

Opting out systems

An opting out or presumed consent system can be expected to encounter the same ethical issues that have been brought up in connection with a scheme that bypasses consent, whether by the family or by the deceased. The impact of opting out policies on donation in various countries has been variable. While the system has been associated with an increase in deceased donation rates (24), one cannot be sure that the improvement could be explained adequately by the presumption of consent since there are usually other important factors to consider (25, 26). In addition, there are reasons to believe that opting out works only if there is an effective way of seeking family consent and there is a reliable and efficient organ registry (27).

One could also wonder why a country like the USA, albeit without an opting out system in place, is doing better than countries with presumed consent. Even if an opting out policy were in place, there are factors that prevent its implementation from resulting in the recovery of more transplantable organs; if it were not in place, there are other processes or social and cultural factors that can be harnessed to yield higher organ recovery rates. To focus on the opting out or the opting in character of the consent system would not be very useful.

Perhaps the most important reason for opposing an opting out system in a developing country like the Philippines is that relevant government institutions are not always efficient in communicating important information to the public. Comprehensive and reliable systems of communication are not in place. It would not be

reasonable to presume that people who do not opt out of the organ donation system, even after the conduct of an information campaign, have had a chance to reflect freely and intelligently on the possible significance and consequences of not opting out. An information campaign addressed broadly to certain groups or sectors cannot be sufficient. One can only be confident that essential information has been conveyed and properly understood if such information is conveyed directly to specific individuals. Done in this way, conveyance and understanding of information can be verified. When communication is directed to the public in general, it would not inspire confidence that the message has been adequately understood.

For example, it would be possible to use verifiable criteria that an aggressive campaign to seek the consent of relatives who have custody of the newly deceased has been successful. The focus on specific individuals makes individual confirmation of degree of understanding and freedom of decision-making possible. This approach to potential sources of transplantable organs should be taken up more seriously in the Philippines, not as a part of an opting out policy but as an independent measure regardless of the context of donor enlistment. In this regard, one should see the importance of an efficient and comprehensive system of donor registration. Such a system is badly needed for the purpose of implementing a serious programme that could have reasonable prospects of success.

Donor registration

In June 2002, Administrative Order No. 124 (28) issued by the Secretary of Health of the Philippines provided for the creation of a Donors/Recipients Registry Unit that was to be responsible for preparing a list of all living non-related donors (LNRDs) and lists of all patients seeking kidney transplantation using LNRDs. The registry unit was to be responsible also for developing a mechanism for comprehensive psychosocial and economic profiling of the prospective donors and for facilitating transplantation, organ exchange, as well as information/technical exchange. It was clear that the focus of that administrative order and the registry unit was on living donors. One can now say in hindsight that the accent

on living donors had the effect of crowding out deceased organ donation. As pointed out above, the number of cadaveric donations ranged only from 10 to 29 between 2002 and 2007. In 2011, the number of cadaveric donations rose to 88. One can only hope at this point that a determined effort to increase cadaveric donations would reverse the trend in relation to living organ donation.

In 2010, another administrative order was issued by another Secretary of Health creating, among other agencies, the Philippine Network for Organ Sharing (29). Officially established on 10 June 2010, the Network was mandated to implement policies on deceased donor allocation, act as the central coordinating body to ensure that all donor organs from deceased donors are allocated according to established criteria, and to maintain national registries of kidney transplants performed, of living related and non-related donors, and of all patients seeking kidney transplantation. The mandate for the Network represents an improvement on the mandate for the Registry Unit created in 2002 in that the newer network clearly encompasses deceased organ donation. One has to be clear about the specific steps that need to be taken in order to ensure that the initiative translates into more actual transplants as it moves forward.

One of the problems that need to be overcome has to do with the crowding out effect of living non-related organ donations on deceased organ donation. The situation has hardly improved since then. Whereas transplants from Filipinos to unrelated foreigners have been stopped, transplants between unrelated Filipinos abound. We still read many accounts of misrepresentation, monetary compensation, coercion, and illegal detention pertaining to transplants from unrelated living donors (19, 30-32).

Efforts at donor registration in the Philippines have had to deal with bureaucratic hurdles. One example relates to competition among hospitals with transplant facilities. Transplant facilities appear to have pursued donor recruitment on their own, thus posing a barrier to an expanded and dynamic system of sharing that could improve the chances of finding the best matches among donors and recipients. In addition, there is the matter of harmonising the tasks and involvement of foundations that have

given financial and other types of support for the transplantation of organs from resource-challenged donors. Institutions organised for a noble and charitable purpose could occasionally engage in rivalry and thereby jeopardise the very purpose for which they have been established. More effort should perhaps be invested in streamlining procedures across institutions and people responsible for perpetrating bureaucratic obstacles to urgent beneficent initiatives should be made to realise the ethical (or unethical) impact of their action or inaction.

Against this backdrop, it is heartening to note that PHILNOS has been very active in donor registry recruitment. For example, a recent activity has been touted as a potential entry for the Guinness Book of World Records for “Most people to sign up as organ donors for one hour single site” (1). The event took place on 28 February 2014, when 3548 registrations were reported at the Polytechnic University of the Philippines in Manila and 2981 registrations were reported in La Union, a province north of Manila, thus beating the previous record of 2755 for one-hour single-site registrations at a similar event in Gujarat in India on 17 September 2013.

However, a hefty increase in donor registrations does not necessarily translate into a corresponding increase in the number of deceased donor transplantations. In the USA, a “proliferation of donor registries ... since 2006, ... [has seen] the total number of registrants increasing from approximately 60 million to 100 million people.” Moreover, “in all 50 states, an individual’s designation as a registered donor is now honored with no further requirement for family authorization.” Unfortunately, “... there has been a disconcerting lack of growth in the number of deceased donor organ transplantations taking place” (33).

This point should not be lost on those responsible for improving donor registration in the Philippines. The increase in registration has to be complemented by an improvement in the attitudes of family members. The attitude needs to be characterised by an enlightened understanding of the significance of donor registration and a willingness to support the declared intent of the registrant after her death. When authorities try to bypass family members

altogether on the grounds that there is no legal requirement to seek family authorisation, they run the risk of generating controversies that create distrust on the part of the public for the institution of organ transplantation in general. One reason why this kind of policy generates controversy is that a legal authorisation does not necessarily convey a privilege that the bereaved recognise as ethical.

Donors with infections

The use of transplantable organs from people with documented infections can also add to the donor pool. This should be seriously taken into account as people infected with human immunodeficiency virus (HIV) have been shown to have acceptable long-term outcomes from transplants (34 - 37). In the Philippines, the impact could be significant considering that the number of HIV-infected persons has been reported to be rising at a “fast and furious” rate (38) with UNICEF recording a 79% increase in newly reported HIV cases, compared to the same period in 2012. Moreover, 1 out of 3 new infections are found among the 1524-year-old population (39), suggesting that prospective transplant recipients could have a lot more benefit from the procedure, should it become necessary. This can be supported by findings of initial success in transplanting kidneys from HIV-positive donors to HIV-infected recipients. Reporting about their experience, Muller and Mendelson observed: “12 months after transplantation, all patients had good renal function, did not have clinically significant graft rejection, and have not needed dialysis since the procedure” (40)

Apart from ethical concerns about the safety of recipients of organs from donors with known infections, controversies may arise regarding the eligibility of transplant beneficiaries with similarly dangerous infections. In transplanting organs from donors with infections to recipients with infections, it may be argued that the latter will provide unfair competition to those without similar infections, all other things being equal. Medically, they will not have equal chances of survival after transplant as possible recipients who do not have such infections.

A possible response might invoke solidarity one HIV patient acting in solidarity with another, although the donor would have been dead at the time of transplant as the reference is to deceased donors. As HIV patients share concerns, they can also share transplant organs (posthumously for one of the parties). One could speak of the identification with others of the same kind that draws them together to depend on one another for their specific needs or to help to provide for those needs. Even as current policies actually discourage transplants between infected and non-infected patients, it would be useful to keep an open mind about the possible involvement of HIV-infected persons either as eligible transplant recipients or as posthumous sources of transplant organs.

Financial assistance for donors

The use of financial incentives to make more organs available for transplant has always aroused controversy. Are there significant ethical differences between financial incentives for living organ donation and those for dead organ donation? Would financial incentives be ethically different from financial assistance of some other kind? The Nuffield Council (41) appears to have thought there are significant differences among these that could be relevant in considering some forms of intervention that may not necessarily be incompatible with an approach to donation that rests on altruism:

We distinguish between altruist-focused interventions (that act to remove disincentives from, or provide a spur to, those already inclined to donate); and non-altruist-focused interventions (where the reward offered to the potential donor is intended alone to be sufficient to prompt action)...: (41:p 5)

The reimbursement of funeral expenses.....is ethically difficult. If offered directly to bereaved families who would otherwise refuse permission, it would very clearly constitute a 'non-altruist-focused intervention'. While there would be no risk of the donor suffering physical harm, it might be argued that any decision by their family to consent to donation solely for financial reasons would constitute a very clear example of

that person's body being used as a means for others' ends and not as end in itself.

The situation would seem rather different if the payment of funeral expenses was triggered by the future donor signing up to the ODR (Organ Donor Registry), rather than being offered to the bereaved relatives at the time of death. To the extent that our Intervention Ladder is appropriate in such a family-based scenario, the intervention might constitute 'rung 4': acting as a final spur for a person already inclined to donate, with the added altruistic feature that others, and not the donor themselves, would benefit. Alternatively, the incentive might seem sufficiently strong for someone to decide to register as a donor simply to spare their relatives the financial burden of a funeral. However, in such a case, the decision would still include an altruistic component, with the aim to benefit others (the donor's relatives)... (41:p 174-5).

The Intervention ladder consists of six rungs, the fifth and sixth of which are regarded as not being acceptable because they serve as incentives that encourage those who would not otherwise donate or that leave the donor in a better financial position as a result of donating.

Is it ethically relevant that whereas in the case of living donation the person who could be incentivised to donate is the person whose organ is proposed for transplant, in the case of dead organ donation it is the bereaved family that could be incentivised to make a donation out of a relative's organ(s)? Ethical issues arising from cases of the first type are not necessarily applicable to cases of the second type. This point has implications for the way we interpret some of the rungs in the Nuffield Council's Intervention Ladder, especially when we have to come to grips with practical realities characterising the context in which financial assistance is sought by or given to bereaved relatives of prospective organ sources.

By looking at practical realities, one can highlight not only (i) the fact that in many developing countries many families are unable to provide, on their own, for a dignified or decent burial or to pay

for the cost of hospitalisation that may have come unexpectedly before the death of the relative, but also (ii) the narrow temporal window of opportunity for transplant coordinators to communicate with the bereaved about organ donation.

In many cases in the Philippines, the stress and confusion associated with failure to provide a decent burial or to pay hospital bills become disincentives for organ donation. As transplant coordinators tell us, these are even disincentives for a mere conversation about organ donation. It would be almost foolish to start a conversation in the Philippines with the family of the deceased about the possibility of organ retrieval for the purpose of transplantation when that family has to deal with issues about hospital and funeral expenses.

**Removing disincentives versus providing incentives:
a tough call when there is a narrow window of
opportunity to strike a conversation with the bereaved**

Would it make a difference that an offer of assistance constitutes the removal of a disincentive rather than the provision of an incentive? Would it make an ethically significant difference if material assistance were offered or provided by a party different from that which is responsible for exploring the possibility of organ donation? It is not easy to provide answers without looking at the details of actual circumstances.

And what if a transplant coordinator waits until an agent for a charitable organisation has had a chance to inform the bereaved about the assistance they are willing to provide before quickly introducing a conversation about organ donation? Seizing the opportunity in this way makes sense because there is a very narrow window of opportunity to engage in a conversation exploring the possibility of organ donation with the bereaved relatives between the time of the declaration of death and the retrieval of a transplantable organ.

One can imagine a transplant coordinator having a database of charitable organisations and local politicians who are willing to provide material assistance to people in this kind of situation and

offers information to the bereaved before initiating talk about the possibility of an organ donation. It would not be correct to say that she is providing compensation for a transplantable organ but would she be exploiting financial assistance provided by another party in an unacceptable manner? Could she not be regarded as attempting to overcome a disincentive?

In these situations, the notion of compensation or bribe may not come into the picture at all. An urgent need for material assistance arises independently of the possibility of organ donation. Because of the narrow time frame, and because there are different parties talking to the bereaved, things can easily get mixed up.

There are many informal mechanisms for providing material assistance to the bereaved that are in place, regardless of the possibility of organ donation. For many who are poor, the absence of material assistance for a decent burial or for settling hospital expenses pose obstacles and disincentives to organ donation for the simple reason that bereaved relatives would be too worried about these things to have clarity of mind to even consider the possibility of donating the dead's organs. Preoccupation with these material concerns is something that needs to be overcome if conversation about the possibility of an organ donation is to be introduced at all. Many opportunities for altruistic organ donation could be lost if there is not enough readiness for these types of situations.

When obstacles exist in the kind of situation described, the matter of donating or not donating has not yet come into the picture one could not correctly speak of a disinclination that could be overturned by an action meant for the purpose of "offering associated benefits in kind to encourage those who would not otherwise have contemplated donating to consider doing so," placing it on the "non-altruist focused" fifth rung of the Nuffield Intervention Ladder. There may not be an inclination because the matter has not been brought to the bereaved relatives' attention but to say outright that there is a disinclination (not the same as not having an inclination) is to underestimate the capacity of the poor (or poor relatives) for altruism.

While occasions such as these could provide opportunities for the exploitation of the vulnerabilities of the poor, these could also be excellent opportunities for the poor to be able to exhibit positive virtues, including altruistic organ giving. The latter should not be ruled out altogether because of a general desire to protect those who may be abused. Rather than an absolute prohibition, what is perhaps more appropriate is a calibrated response that would give transplant coordinators confidence to speak to bereaved families without fear that they could be stepping into a situation without showing sensitivity to the families' concerns, or that they could be seen as taking advantage of the vulnerabilities of the poor. Specific protocols for dealing with these circumstances can be formulated, and should be observed. In the context described, material assistance given to the bereaved is not to be construed necessarily as compensation. In resource-challenged settings, assistance of the kind is commonplace and a real necessity –something that the poor have come to expect already, in the absence of better alternatives to look forward to. They have to be carefully set up and monitored.

What has to be avoided is the association of this assistance (or offer of assistance) with organ donation. Obviously, the narrow temporal window for any conversations with the bereaved could present problems. When the motorcycle accident victim is declared brain dead, the funeral parlour representative could be waiting for the first opportunity to offer services, encouraged perhaps by a promise that cost is going to be covered by a predictable and reliable local politician known to their company. A good transplant coordinator also has to be on the scene, ready to grab the first opportunity to start a conversation. Understandably, it will be most prudent for the coordinator to wait until the relatives are assured that their burial and hospital costs are going to be covered. But the transplant coordinator cannot wait too long. As mentioned above, what can be recommended is the adoption of specific protocols to be observed in introducing conversations exploring the possibility of organ donation that clearly state that the organ donation is not a precondition for any material assistance (funeral or hospital costs) offered by anybody.

Conclusion

The analysis above indicates assistance that would be acceptable to the Nuffield Intervention Ladder. There would have to be clear protocols indicating what information needs to be given to relatives and when and how that information is going to be provided. When all announcements are made in a timely manner and protocols are clearly defined and observed, the possibility of making an organ donation could be something for family members to discuss among themselves and prepare for. To be sure, there is a lack of specificity in the proposal at this point.

It should be added that transparency and fairness have to be observed at all stages. In the interest of transparency, pertinent information about the policy has to be disseminated in advance and not be limited only to those who are facing bereavement already. In addition, the approach has to be the same for all and not only for those who are economically challenged.

Something also needs to be said about the prevailing idea that organ transplants from living donors are medically better than transplants from dead donors. Some physicians have been known to tell their patients who are in need of transplants to wait until they can have living donors rather than go for cadaver organs. This attitude has encouraged dependence on living donors by renal patients and, to that extent, has resulted in the crowding out of dead donor transplants.

While it may be true for some specific kidney patients that it would be better for them to receive a transplant from a living donor than for a dead organ donor, it is misleading to declare in general that transplants from living donors are better than organ transplants from dead donors. To say the latter is to look at things purely from the perspective of the recipient. However, better or worse has to be seen from the perspective of the two parties involved and if we take into account the risks to the organ donor we can easily see why it is grossly erroneous to say that the use of transplant organs from living donors is always better than the use of transplant organs from dead donors.

It seems we have not taken the help that the dead can provide seriously enough and the living could be suffering because of

that attitude. Now is as good a time to start as any, but we have to make sure that organ trafficking and the exploitation of living donors is not crowding out the opportunity to shift the burden of responsibility to the dead.

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Unrelated renal transplantation: an ethical enigma

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Abstract

End-stage renal disease (ESRD) is a condition better discussed than suffered. People suffering from ESRD are at a disadvantage not only financially, but also emotionally and in terms of the quality of their lives.

The majority of their productive time is spent in hospital, on dialysis machines, or in the search for a suitable kidney donor, so that they may be able to improve upon the quality of their remaining lifespan. Only a “lucky few” are able to find a suitable matching donor, be it living (related) or a cadaver, whilst the others are left to fend for themselves.

As the supply fails to cope with the demand, people go to the extent of exploring the pool of “unrelated donors”. Though not legalised yet, this is one domain yet to be explored in its entirety, both on humanitarian as well as ethical grounds.

Our current work hopes to highlight this scenario and also provides a few options that may well become “ethically acceptable” in the not-so-far future.

Introduction

*“Kidneys are special, in their own way...
So special are they, that, they have their own day...
From removal of wastes.... to helping our health gain.....
Be it morning or evening.... sunshine or rain.”*

The above stanza typically exemplifies the work put in by our kidneys, non-stop, to keep us healthy. Like any tireless machine,

they are continuously at work to ensure that no “toxicity” ever sets in. What would happen if this God-given gift developed fatigue and closed shop?

A hypothetical scenario

Consider a hypothetical scenario:

Pooja, an 18-year-old girl, is her parents’ only child. Theirs is a nuclear family, belonging to the upper socioeconomic strata.

What is wrong with this, one would ask. Well, Pooja has been surviving on alternate-day haemodialysis since the past five years because she suffers from end-stage renal disease (ESRD). She spends more than 60% of her time shuttling between home and hospital, her parents in tow, utilising the remainder of her time on her studies and recreation. Where did she go wrong? Did she not take good care of her kidneys?

Why can she not go in for a renal transplant and replace her machinery? She can, but she needs a donor. Her parents, though more than willing, have been ruled out on account of ABO incompatibility. She was enrolled in the cadaveric transplant wait list five years ago. Over this period, she has moved up from a dismal wait list number of 275 to a probable 120. It is safe to say that she will figure on the operation theatre list only after another 3–4 years.

What is Pooja’s fault here? Born and brought up in a nuclear, modern family, there are hardly any other relatives, willing to donate their kidneys, simply out of “love and affection” for her, as acceptable under the norms of the “Transplantation of Human Organs Act (THO Act) (1).

The Transplantation of Human Organs Act and pitfalls

The THO Act (1) was passed in 1994, to regulate the removal, storage and transplantation of human organs for therapeutic purposes, and for the prevention of commercial dealings in human organs. It defines all possible organ donors, as well as the role of various regulatory bodies. However, it also goes on to state that in the absence of a first-degree relative (mother, father, son, daughter,

brother, sister, spouse and pending amendment, grandparents), special permission may be obtained from a government-appointed authorisation committee to prove that the motive of donation is “purely altruism and affection” for the recipient (1). It is this very loophole of “love and affection” that has been repeatedly used, or rather misused, to legalise unrelated renal transplants (1, 2).

In view of the ever expanding pool of ESRD patients, the rift between the demand and supply of “kidneys” has only widened, resulting in the widespread use of the misnomer of “love and affection” (1, 2). In addition, this provision has led to a tremendous increase in “transplant tourism” from those countries with strict law enforcement agencies to countries such as India and China, where law enforcement is somewhat lax. As a result, such countries have been nicknamed “warehouses for kidneys” and for India the specific term is “The Great Indian Kidney Bazaar” (2, 3, 4).

Its ramifications have led to a “*wedding among unequals*”, viz an organ-wedding between wealthy, but desperate people, dependent on dialysis machines, with those economically impoverished destitute, who are more than willing to part with one of their kidneys, for short-term monetary gains to pay off their debts, without having any understanding of the physical and psychological implications (4, 5). Strangely, surveys carried out by various non-governmental organisations (NGOs) found that even five years after such commercial donation, more than 84% of such donors were still drowning in various debts (despite receiving the promised sum of money) (6).

The problem

So, where does the crux of the problem lie? Have such nefarious activities become widely accepted because of the improper enforcement of the THO Act or is it a societal issue? The dictum “*when you can buy one, why donate*” (5, 6) still holds very much true. What we need to explore is whether in today’s self-centred, self-proclaimed “modern” society, in which there is scant bonding between relations, there is any scope of expanding the law so as to legalise unrelated transplants.

In India, despite the THO Act (1), neither has organ commerce stopped, nor has the number of deceased donors increased to take care of the organ shortage. India currently has a deceased donation rate of 0.05–0.08/million population (7), which is way below the requirement.

This entire social scenario has led to a boom in unrelated transplantation, mostly under the cloak of a legal authority from an authorisation committee that takes advantage of the loopholes in the interpretation of the THOA Act. Evidence of this lies in the various kidney racket scams over the years, eg the Gurgaon kidney scam (2008) and the Lucknow scam (2011) (8). *Prima facie* evidence even suggested the involvement of a senior police officer and a “quack” (8).

These are just a few instances that have come forth into the public domain and these may be just the tip of the iceberg. Hence the need to get to the root of the problem, so as to be able to “nip the evil in the bud”, in an ethically acceptable manner.

So, should Pooja and her economically sound parents pursue this very course? Transplant ethicists would say an overwhelming, “No”, but non-purists would say, “Why not, if they can afford to?”

Let us look at both aspects.

Legalisation of unrelated transplants: good, bad or ugly?

Unrelated organ transplantation has been legalised in countries such as Iran and Singapore, where the basis of legalisation is that most “lawsuits” are filed post-transplantation only if the capital gain promised to the donor has not been paid as committed by the recipient. Hence, an authority that can regulate this *give and take* would not only reduce black marketing and the role of middlemen, but would also ensure that the donor receives adequate compensation in a timely and legal manner (9). Needless to say, this would also help to shorten the long deceased donor transplant waiting lists (7, 9).

What, however, is an “adequate” compensation? As per an American study, a kidney donation subjects the individual to a

loss of around 4.5 years of livelihood, which in monetary terms, can be equated to around USD \$98,000 (10). Needless to say, everyone cannot afford such a colossal sum of money and only a privileged few would benefit (9). Additionally, what would be “adequate” would also vary from country to country. Though the importance of a kidney is the same, be it in a developed or a developing nation, the compensation would never be the same, unless regulated by an appellate authority worldwide.

Taking this a step further, some people have even advocated a legalised “organ auction” to ensure that the donor is adequately compensated by the highest bidder, or synchronously, by the recipient and a government authority specifically set up for this purpose. In today’s society, in which “health insurance” is sacrosanct, altruists have advocated such insurance for these “unrelated donors” so that they are protected, medically and in the long term, against any loss of “productive life-years” due to organ donation, at any later stage and age of life.

Ethicists and disciplinarians would, however, beg to differ. They would say that a “kidney” is not a “commodity” to be bought and sold. They would argue that the procedure of organ donation has short- and long-term effects on the donor as well as his/her family, and this needs thorough understanding and awareness. Organ donors need to be followed up not only in the pre-donation work-up, but also with annual health checkups throughout their life to pre-emptively detect and treat any possible disease or infirmity.

Most unrelated “altruistic” donors and their “unwillingly willing” families are not even aware of the possible aftermath of the procedure or its long-term effects. The only stimulus for donation remains “monetary”, the aim being to overcome immediate socioeconomic difficulties, and as such, these donors may be inadequately worked up for donation so as to fast-track the entire process.

Though the legalisation of unrelated donation may help overcome the acute shortage of organs, it should not be without its own “disclaimer”

The Indian scene and state of mind

Currently, there are over 120 transplant centres in India, performing around 3000–4000 kidney transplants annually. According to rough estimates, around 15% are unrelated transplants, for which the kidney was donated out of “love and affection” (11). Since the legal appellate authority has no knowledge of such unrelated transplants, it is impossible to judge their exact number both in India and elsewhere, and these figures could just represent what can be extrapolated from the microscopic to the gross level. This, however, does not take away from the overall issue; instead, it makes it all the more important to deal with.

The economic disparity between the donors and recipients makes it very difficult to believe how the downtrodden donors could suddenly develop such affection towards the economically sound recipients. It is evident that despite the fact that the THO Act was passed more than 20 years ago, it has neither curbed commerce, nor helped in the promotion of deceased donation to bridge the rift.

If organised properly and in a timely manner, deceased organ donation, commonly known as “cadaveric transplant”, has the potential to take care of the greater part of the demand for renal transplantation in a particular state. These transplants, though technically more demanding and requiring a higher level of organisational skill, have gained acceptance in the culture of only very few states in India. These are Kerala, Gujarat, Tamil Nadu, Andhra Pradesh and Maharashtra. Probably it is the people in these states who are truly following the norm of “charity begins at home” simply by donating the organs of their deceased near and dear ones.

The organisation of such cadaveric transplantation has also been left to certain NGOs, with little or no cooperation from government agencies. Not only does this put increased pressure on the already overloaded “living donation programme”, but it also leads to a manifold wastage of lifesaving organs from potential brain-dead donors or those who have succumbed to road traffic accidents. A very high level of motivation and compassion is mandatory

to orchestrate a deceased donor transplant programme across all states in the country, as well as worldwide.

Cultural and religious beliefs form another roadblock to this programme. In countries such as India, religious beliefs generally discourage organ harvesting from cadavers, thus making it hard to convince relatives to donate the organs of their loved ones whilst the heart is still beating. A brain-dead patient, kept “alive” via a life support system, looks completely normal and thus, most relatives find it impossible to accept that the person is in a vegetative state and will certainly never allow the removal of organs from the patient. Therefore, to ensure that this huge organ pool does not go to waste, there is a need to bring about a sea change in the sociocultural beliefs of people (11).

On the other hand, what is the harm in letting people with ESRD / chronic kidney disease / renal failure remain on dialysis until they find a cadaveric donor, or until any first-degree relative willingly donates his or her kidney? There is absolutely no harm, but, as per recent Indian data, one must consider how long the 650 government-authorised dialysis units available would be able to sustain the burden of the approximately 80,000 new patients annually diagnosed with ESRD (12, 13).

Renal transplantation generally offers a longer lifespan and better quality of life than long-term dialysis. However, nearly every country is facing an acute shortage of kidneys for transplantation. In the USA, 50,000 individuals are waiting for kidney transplantation, yet only 15,000 kidneys are transplanted annually (5). The shortage is even more severe in developing countries. Even though India has four times the population of the USA, Indian physicians transplant fewer than 4000 kidneys annually, and a number of the organs are received by non-Indian transplant tourists (12, 13, 14).

Another facet of the entire picture is that patients of ESRD have a very poor quality of life and mostly suffer from social neglect due to their substantial “in dialysis” time.

A fervent plea made by a group of 90 Indian patients awaiting renal transplant via the unrelated donor programme against the

ban aptly summarised the situation. They stated: "True, hard destiny forces people to sell their kidneys, but by this act, they bless ill-fated people like us with a new lease of life. This country has the unique distinction of giving rebirth to ESRD patients." (15). However, they also clarified that they are not opposed to the bill, but urged the government to allow the unrelated donor programme to continue till such time as all hospitals switch over totally to the cadaveric programme.

Introspection

The main reason for the increasing number of patients on the renal transplant waiting lists is the steady growth of a patient population that needs renal replacement therapy worldwide. At the end of 2001, as per WHO estimates, approximately 1,479,000 people were alive in the world just because they had access to dialysis and renal transplant facilities. This number increased to 1,783,000 by the end of 2004 and exponentially thereafter (14,15). The major factors that contribute to the continuous growth in the number of patients with ESRD are universal aging of populations, higher life expectancy of treated patients with ESRD, and the increasing access of a generally younger patient population from developing countries to dialysis and renal transplantation facilities. Effective strategies to prevent the increase in the number of patients with ESRD or new treatment modalities that are either superior to or an alternative to dialysis and renal transplantation are not expected to be available at least in the coming decade. Herein lies the need to find alternative feasible solutions.

According to a recent report (15), in a case similar to that of Pooja's, a transplant team at Mumbai has successfully carried out a transplant from mother to son, despite ABO incompatibility. The only glitch, so to say, is that the patient needed plasma exchange and induction via Rituximab, and was admitted almost 15 days prior to the actual transplant, which exponentially increased the costs to nearly 7 times the normal. How many people can afford this in an impoverished and developing country, or even in a developed country, is a matter of debate. Also, the long-term follow-up results are not yet available, so it cannot be safely extended to become a standard of care.

Role of marginal donors:

Marginal donors” or “expanded criteria donors” are a pool of the population that needs immediate attention so as to reduce the dearth of organs. This involves using suboptimal cadaveric renal allografts, non-heart-beating donors or living donors with acceptable medical risks (16). This expanded pool would include elderly living donors (with an age-corrected glomerular filtration rate), living hypertensive, diabetic or proteinuric donors, living dyslipidaemic donors, living donors with a history of malignancy, as well as donors with a history of nephrolithiasis (16).

“Expanded criteria donors”, a category coded in 2002, are defined as kidney donors over the age of 60 years without any co-morbidity or donors over the age of 50 years with any two co-morbidities out of hypertension, death from a cerebrovascular accident or serum creatinine levels of above 1.5 mg/dl (17). The upper age limit for such donation has still not been defined (17).

A shortcoming could be the overall graft survival from such donors, which has been reported to be overall inferior to graft survival in recipients of kidneys from donors who meet the standard criteria and are medically fit (18, 19).

Despite the pitfalls of “marginal donation”, it would probably still lead to an increase in the legally and socially acceptable related organ transplantation rate. Moreover, such donation has been found to be more cost-effective for patients than is leading a life that is dialysis-dependent in the long term (20).

As is rightly said, “Every single drop accumulates to form an ocean.” So, too, every single acceptable kidney would help to improve the lives of the ocean of people with renal failure, struggling to find a medically, ethically and legally acceptable donor.

Future scope

Another immediate strategy that can be utilised to prevent organ exhaustion is “swap or pair transplants”. This involves an exchange of kidneys between two pairs of people (two couples) based on their ABO compatibility, to benefit each other’s recipient. This would probably be the most ethical mode of unrelated transplantation.

New cost-efficient therapies are the need of the hour to salvage the situation for patients with renal failure. Man, by nature, is a thinking animal and medical science is evolving by leaps and bounds. The role of tissue engineering, stem cells or “*in-vitro* kidneys” in providing alternative organ resources needs to be explored in the near future.

One such step in this direction has been taken by researchers in the USA, where a prototype of a surgically implantable, artificial kidney has been developed. Human trials of these “wear-on” kidneys are awaited before they can be accepted into the field of “renal transplantation”. Till such time, it would probably be safe to say that unrelated renal transplantation forms the “ledge of a precipice”.

Perhaps the following paragraph gives an apt insight into the mindset of an ESRD patient and his family:

Donate to a stranger.....

Keep another family whole....

While filling your heart and inspiring your soul.....

Who knows, when you give a part of yourself.....

*You'll end up more fulfilled and complete,
much much more, than before....*

Thus, it would be safe to say that though transplant recipients may obtain a “net gain” and the impoverished kidney donors may incur a “net loss” in the long term, there are no trials or studies to prove the same, and how the right balance – legally, socially as well as ethically – can be obtained remains to be debated so that there is a “win-win” situation for all.

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Trade in kidneys is ethically intolerable

DOMINIQUE E MARTIN

Abstract

In India, as in most countries where trade in human organs is legally prohibited, policies governing transplantation from living donors are designed to identify and exclude prospective donors who have a commercial interest in donation. The effective implementation of such policies requires resources, training and motivation on the part of health professionals responsible for organ procurement and transplantation. If professionals are unconvinced by or unfamiliar with the ethical justification of the relevant laws and policies, they may fail to perform a robust evaluation of prospective donors and transplant candidates, and to act on suspicions or evidence of illicit activities. I comment here on a recent paper by Aggarwal and Adhikary (2016), in which the authors imply that tolerance of illicit commercialism in living kidney donation programmes is not unreasonable, given the insufficiency of kidneys available for transplantation. I argue that such tolerance is unethical not only because of the harmful consequences of kidney trafficking, but because professional tolerance of commercialism undermines public trust in organ procurement programmes and impairs the development of sustainable donation and transplant systems.

Introduction

The use of financial incentives to increase living kidney “donation” has been the subject of debate among ethicists and transplant professionals since the 1980s. The persisting problem of insufficient supply of human kidneys for transplantation in many countries is repeatedly cited as a rationale for the introduction of legal markets in kidneys (1). Illicit trade in kidneys also remains a widespread problem, and some commentators have argued that

the introduction of regulated markets – sometimes described as “incentive programmes” – would reduce such trafficking and prevent the harms associated with the black market (eg. 2). Aggarwal and Adhikary draw attention to this complex issue in the context of India, presenting an ambivalent position on the incentive debate (3). In this commentary, I clarify some of the points they raise and contend that a permissive approach to kidney trafficking is ethically unjustifiable. Specifically, I argue that Aggarwal and Adhikary underestimate the negative impact of kidney trafficking on organ sellers, transplant recipients, and the broader organ donation and transplantation system. I further argue that regulated incentive programmes are likely to replicate many harms associated with illicit kidney markets and suggest that a more robust approach to the prevention of kidney trafficking, together with greater investment in efforts to reduce the burden of end-stage renal disease (ESRD) and to facilitate and encourage living and deceased donation, will ultimately improve equitable access to transplantation in India.

The law governing transplantation in India

Aggarwal and Adhikary refer to the Transplantation of Human Organs Act (THOA), 1994, which was enacted in 1995 (4). It specifically prohibited payment for organs, and required review by an authorisation committee of all prospective living donors who are unrelated to the intended recipient, defined as all those not spouses, children, parents or siblings, but who wish to donate “by reason of affection or attachment towards the recipient or for any other special reasons” (4).¹ This Act was notably amended in 2008 and 2011 (7), partially to address concerns that the process of the review of prospective unrelated donors was not effective in identifying and addressing cases in which paid “donors” were presented as altruistic unrelated donors. The amended Act now requires verification and countersigning of documents attesting to the identities of and relationships between prospective donors and recipients, and additional approvals for foreign nationals (7). The Act also lays down greater penalties for those convicted of illegal activities (7).

The impact of these recent amendments to the THOA may not be observed for some time. The successful implementation of new

policies and guidelines requires motivation, training and a removal of barriers, which may include the negative attitudes of some health professionals. If the ambivalence of Aggarwal and Adhikary reflects that of the broader community of transplant professionals in India, it is conceivable that many may be reluctant to change their practice so as to comply, for example, with more stringent requirements for prospective donor evaluation. Fortunately, the reports of the scandals concerning domestic trafficking noted by Aggarwal and Adhikary suggest that authorities within India support the enforcement of this law. Anecdotally, recent reports of Indians travelling to Sri Lanka to buy and sell kidneys suggest that opportunities to sell within India may have been reduced (8). Nevertheless, trade in organs undoubtedly persists in India, and the support of all health professionals involved in donation and transplantation is essential for the success of efforts to eliminate this market and to ethically provide opportunities for transplantation within India.

Regardless of its legality, trade in kidneys is an unhelpful “solution” to shortages

Aggarwal and Adhikary suggest that it is unclear whether recipients of commercial transplants benefit and kidney sellers are harmed in the long term. However, evidence from the black market in kidneys in India, Pakistan and elsewhere, and from the legal, albeit poorly regulated market in Iran, shows that kidney sellers do suffer long-term harms (9). Although there are limited data concerning the long-term outcomes, the majority of kidney sellers studied experience a decrease in their economic, psychosocial and physical health status (9). Loss of employment opportunities, social stigmatisation, and ill health experienced following the sale of a kidney are likely to exert a negative influence on the long-term well-being of kidney sellers and their communities, especially in the absence of a substantial increase in their financial status as a result of the sale.

Recipients of transplants using organs from paid “donors” may also fail to obtain the anticipated benefits of their purchase. Those who travel abroad to purchase kidneys (“transplant tourists”)

have higher rates of complications such as infection and poorer graft survival (10). Within domestic markets, a study in Pakistan found that recipients of kidneys from paid donors were thrice as likely to suffer complications as those receiving related donor transplants, with five-year graft survival being 45% and 80%, respectively (11).

Illegal trade in kidneys has a negative impact on legitimate programmes of organ donation and transplantation. As Aggarwal and Adhikary note, where there is an opportunity to buy a kidney, people are often unwilling to solicit or accept a kidney from a related donor. Awareness of the trade among the public and health professionals fosters a perception that access to transplantation is determined by ability to pay, and that professionals involved in donation and transplantation are likely to be influenced by opportunities to profit from organ procurement. Unfortunately, such perspectives may partly reflect the reality. The resultant distrust in the integrity and justice of programmes and professionals responsible for organ procurement from the living and the deceased, and the stigmatisation of donation as a commercial activity performed by the financially desperate undermine participation in altruistic donation opportunities.

Despite the claims of those who advocate a regulated market in kidneys from living “donors”, many of the ethical concerns about illegal trade are unlikely to be addressed through regulation. I have argued elsewhere that market regulation may be less effective in addressing concerns about harms than advocates suggest, even in a more robustly regulated healthcare setting such as that of the USA (12).

This is partly due to the fact that where payments are used to incentivise kidney “donation”, the burden of donation will fall disproportionately upon the poorest members of society. This population is particularly vulnerable to the risks associated with kidney donation, as its members often lack resources such as access to primary health services which may serve as protective factors; and face higher lifetime risks of illness, injury and psychosocial insults that may influence the outcomes of elective nephrectomy (12). Careful screening of all prospective kidney donors to ensure

that risk factors may be addressed, eg through the provision of long-term follow-up care, and that high-risk candidates are deferred is essential. The poor should not be categorically excluded from donation opportunities – the success of the altruistic related donor programme at the Sindh Institute of Urology and Transplantation in Pakistan shows that a predominantly poor donor population may have excellent outcomes (11, 13) – but the provision of a lump sum payment designed to recruit rather than to care for donors exploits society's most vulnerable for the benefit of the rich.

Iran's oft-cited "model" of a regulated market in kidneys reveals disturbing similarities with the black markets of Asia and Latin America. Kidney sellers are predominantly poor, young and under-educated men (14). The prices of kidneys vary according to the availability and desperation of sellers, and the ability of transplant candidates to pay (15). The quality of the evaluation of prospective kidney sellers also varies, and this influences the potential risks accepted by the sellers and recipients. The informed consent process may also be flawed, and there is limited follow-up care and monitoring of sellers, such that the actual risks of selling a kidney in Iran are difficult to estimate (14). The existence of a market has effectively "crowded out" living related donation, with stigmatisation not only of living but also deceased donation, despite the fact that payments are not made to deceased donor families. Although not all reports of outcomes for kidney sellers in Iran are negative, it is by no means an exemplar of ethical policy and practice. Furthermore, it has not solved the problem of organ shortages in Iran; a recent report states unequivocally that "the never disappearing waiting list for kidney transplantation [in Iran] will be growing steadily" (16).

Claims in the USA that the current shortage of kidneys there would be resolved by the introduction of an "incentive programme" for donors remain speculative (1). In the Indian context, it is probable that the creation of a legal market in kidneys would increase supply at least in the short term, assuming the eligibility criteria for selling a kidney would not exclude those suffering a financial crisis, lacking long-term health insurance and so on. There is a sufficiently large population of Indians for whom selling a kidney

would represent the best – if not the only – economic solution to an immediate financial crisis. Such a market would nevertheless be harmful to the participants, exploitative and inequitable, just like the existing illicit market in kidneys.

Although an individual market transaction may on occasion benefit both transplant recipient and kidney seller, and in many cases will result in the saving of a life, such benefits do not provide sufficient justification for a public policy legalising trade. What an individual may be justified in doing in the absence of alternative options is not always justified on the part of governments and health professionals, who have the obligation to consider the broader impact of individual actions and the interests of all societal members. For example, although lives may regularly be saved when members of the public break into pharmacies to steal medications required by critically ill children, it does not follow that governments should legalise the ad hoc robbery of pharmacies. Rather, governments should consider the most effective, sustainable and least harmful means of achieving the overarching goal of saving lives. With regard to the goal of preventing deaths from ESRD, markets in kidneys are neither the sole, nor the optimal solution; nor are they a solution to endemic poverty.

Ethical solutions to the kidney shortage

There is enormous potential to develop both living and deceased organ donation programmes in India. The success of deceased donation programmes in Tamil Nadu and Chandigarh demonstrate that dramatic improvement is possible in the current performance of organ procurement programmes across India if sufficient efforts are made and support provided (17). In addition, many strategies that have proven successful in other countries are yet to be fully explored in India, such as those noted by Aggarwal and Adhikary: kidney paired donation and the use of extended criteria deceased donors. The costs of becoming a living donor may prevent many from donating to their relatives, especially in the absence of universal health coverage. Financial barriers to living donation have been observed in many countries, and will undoubtedly influence donation rates in India. Reimbursing

– or covering the costs of living donation– and even deceased donation, where necessary – is not ethically contentious: the World Health Organisation, the Declaration of Istanbul, and many national, regional and international professional societies actively encourage efforts to promote financial neutrality in organ donation (5).

Those who cannot afford donation are also likely to be excluded from transplantation due to financial barriers. Thus, when evaluating the scope of the ethical duty to save the lives of those with ESRD and when advocating strategies to address the organ shortage, policy-makers and health professionals must carefully consider whose lives may be inadvertently prioritised, and who may bear the burdens associated with particular strategies. If the aim is indeed to maximise the saving of lives of people with ESRD, the most effective method of doing so is surely to invest in the prevention of ESRD rather than the recruitment of living donors.

Tolerating occasional violations of the THOA on the grounds that deceased donation programmes in India do not yet provide sufficient kidneys for transplantation is not an ethically justifiable strategy. It suggests a lack of moral courage and a willingness to make use of the poor for the sake of the privileged few. All those responsible for legislation, policymaking, and clinical practice in donation and transplantation in India must make an unequivocal commitment to best practice, which means ethical practice. Compromising on ethics undermines the societal and professional foundations on which successful and sustainable altruistic living and deceased donation programmes are built.

Note

¹ The definition of “unrelated donor” differs according to the laws governing organ procurement in each country. The term should not be considered synonymous with paid donors. Covering the costs that may be associated with living donation, such as loss of income during time off work, should also not be confused with payment for organs. Covering such costs does not leave the donor financially better off, and thus provides no financial incentive for donation (5). Aggarwal and Adhikary incorrectly suggest that Singaporean law permits the sale of organs. Like many countries, Singapore permits donation by a range of genetic relatives and emotionally related individuals, and does cover some costs

associated with living donation for eligible donors. However, trade is strictly prohibited and a comprehensive screening programme seeks to identify and prevent commercialism (6).

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Living kidney donation and masked nationalism in Israel

MIRAN EPSTEIN

Abstract

This paper draws attention to a current trend of masked conditional-nationalist living kidney donation in Israel, to which the local transplant system has been turning a blind eye. The paper seeks to make the international transplant and bioethics communities aware of this disturbing trend. It also explains why it is wrong and suggests how to tackle it. Finally, it calls on the Israeli system to bring the practice to a halt for the benefit of all parties involved.

Introduction

In a better world, all organ donations would be unconditional, made to the global pool with no strings attached. Further, the organs would be allocated strictly on the basis of need. Economic considerations, social standing, class, race, ethnicity, faith, gender, nationality, age, reciprocity, friendship and even kinship would play no role in the decision-making process. Social solidarity would be the sole driver, means and end of the transplant enterprise.

Things are different in our world. The vast majority of living donations are conditional. In many cases, the system goes along with the donor's demands. However, even when the donor makes none, as is typically the case with deceased donation, the allocation system often sets its own conditions. Priority to local patients over aliens (also called the *principle of self-sufficiency*) and to those willing to donate to the organ pool over "free riders" are frequently cited examples (1:p 5b; 2).

Whether from the deceased or the living, conditional organ

donation takes two general forms. First, it can be *directed to a related or unrelated individual*. In this case, it would be ethically acceptable and effectively binding, subject to certain terms and conditions. Second, it can be *directed to or withheld from certain groups or types of people*. This form of conditional donation is often sweepingly referred to favourably as *socially directed donation* (3). In the following, I will use the term *sectarian donation*, which I believe is more appropriate, accurate and informative.

Sectarian donation, which is the focus of this article, may under certain circumstances seem moral, or at least not immoral. For example, donation that is directed specifically to children or to a social group that happens to have relatively poor access to organs may arguably be moral. By contrast, donation that actually or even just ostensibly involves racism, nationalism, chauvinism or bigotry of some sort is probably, not to say evidently, immoral, though some scholars would not reject it on this ground alone. They argue that even divisive donations save lives, saving lives being the highest value (4, 5, 6).

In any case, putting aside subjective moral sentiments, sectarian donation is almost invariably in breach of the prevailing international transplant ethic. In other words, the current codes happen to consider it immoral and unacceptable *regardless of the nature of the conditions laid down by the donors*. Exceptions are rare and, at any rate, tangential to solid organ donation. For example, the Australian *Assisted Reproductive Technology Act 2007 (New South Wales)* explicitly permits gamete donors to discriminate against potential recipients on any basis, including race, ethnicity and sexual preference (7).

It is likely that most transplant systems would reject deceased or living organ donations if the donors were to be plain about their sectarian motives. The ethical positions of national systems may not always be set forth in detail, but there is no doubt as to their anti-sectarian spirit.

In 1998, the next-of-kin of a deceased British white man specified that his organs could not be allocated to non-whites. The organs were accepted and allocated to white people who, by coincidence,

would have been the recipients anyway. However, following criticism in the British media, a Department of Health investigation concluded, among other things, that “racist conditions are completely abhorrent” and should be prohibited (8, 9).

The National Health Service (NHS) Blood and Transplant policy is even wider: “It is a fundamental principle of the UK donation programme that organs are freely and unconditionally given.” (10).

The Transplantation Society (TTS) takes a similar position and so does the US United Network for Organ Sharing (UNOS). According to the former, “...[conditions] imposed on the selection of recipients interfere with the principles of justice and equity, and sometimes also the principle of utility. In this situation, the rights of the recipients based on these ethical principles overrule the donor’s right to autonomy. Despite the organ shortage, the offer for donation should, therefore, be declined.” (11).

Elaborating on the ethical principles in organ donation, the UNOS states: “UNOS has long opposed donations directed to a social group (based on race, religion, gender, or sexual orientation).” (12).

In view of this global ethical stance, one may assume that sectarian donations can take place only if they conceal themselves behind some ethical guise.

This paper draws attention to a current trend of masked sectarian living kidney donation in Israel, to which the local transplant system has been turning a blind eye. The paper seeks to make the international transplant and bioethics communities aware of this trend and the way it conceals itself. It also explains why it is wrong and suggests how to tackle it. Finally, it calls on the Israeli system to bring the practice to a halt for the benefit of all parties involved.

The Israeli case

The 2008 Declaration of Istanbul on Organ Trafficking and Transplant Tourism marked the launch of a concerted international campaign against these disturbing practices (1). As part of this

campaign, one article drew attention to the hitherto ignored potential of altruistic, directed, individual-to-individual living unrelated donation (LURD), which is, in principle, ethically acceptable and widely encouraged, to conceal commerce in organs (13). The risk still exists. Most transplant programmes require a detailed psychological evaluation to assess the donor's capacity to make an informed and free decision, and to rule out commerce (14). However, the tests remain weak for two reasons. First, monetary transaction is difficult to identify as both donor and recipient are usually coached to deceive the system of oversight. Second, and perhaps more crucially, the transplant system fears that more rigorous tests would be likely to diminish the number of acceptable donations (15).

There is, however, another hazard associated with altruistic individual-to-individual LURD that has so far received no attention at all: the risk that it conceals a sectarian condition.

The Israeli media have recently reported an increasingly popular trend of conditional living kidney donation from Jews to Jews, disguised as altruistic, directed individual-to-individual LURD. It is definitely a trend, and not some isolated cases. Taking place between total strangers, the donations are brokered by a Haredi charity, called *Matnat Chaim* (Gift of Life) – Volunteers for Kidney Transplantation, which matches donors and recipients. It has recorded more than 331 donations since 2009, against a waiting list of 850 (16, 17, 18). The trend now seems to involve other countries as well. The charity reports that on May 18, 2016, the London-based Royal Free Hospital performed a transplant involving an Israeli donor and a British recipient, who had been “brought together” under the auspices of the charity (19, 20).

The chairman of *Matnat Chaim*, Rabbi Yeshayahu Haber, regards this trend as wonderfully unique: “This is the only country in the world with so many people donating their kidneys voluntarily to strangers” (in the following, all translations from Hebrew are mine, M.E.) (18). Haber also reveals the motivation: “Most donors wish to ‘save a Jewish soul’; thus most recipients are Jews.” (21). Interviewing a group of volunteers of the charity, one reporter writes:

Would you be willing to donate a kidney to a non-Jew as well? They find the question difficult to answer. Rabbi Shapira volunteers to answer on their behalf: "One person says, 'I am willing to donate a kidney to my brother, or even to my cousin, but not to my neighbour. I am saying I am willing to donate to my brother, and also to my cousin, and also to the cousin of the cousin, and also to my people in general. Thus my family includes my people. I have no problem donating to an Arab ... but on condition that someone from his family donate a kidney to a Jew. I am willing to put myself at risk so that eventually my extended family – that is, my people – will live; I don't mind if this is achieved directly or indirectly.'" (17).

Another reporter notes:

But if everything so far has seemed philanthropic, pure and altruistic, we now arrive at the most controversial point about *Matnat Chaim*: the charity allows the donors to direct their donation to recipients of some specific kind. They can choose the sex of the recipient; they can choose their age; and they can choose their nationality. So far, all donors have made one condition: the recipient must be a Jew (22).

What is more, the Israeli transplant community and its system of oversight have been collaborating to keep this sectarian trend alive, turning a blind eye to the fictitious nature of its ethical guise. Paulina Katz, a transplant coordinator in a major Tel Aviv hospital, says, "Those who donate through the National Transplant Center may not decide who will receive their kidney. The charity, which connects donor and recipient, is in fact a bypass. ... They come to us as a couple, and we do not intervene in the matching process." (21).

Professor Eytan Mor, one of Israel's most senior transplant surgeons, adds, "Honestly, I avoid talking about this phenomenon in international conferences. I know we will be criticized."

Interestingly, it is not the sectarian-unethical nature of the practice that he seeks to hide from potential critics. Apparently, it is well hidden from him, too. Rather, he wishes to avoid accusations that "the donation reflects not free will, but rabbinical pressures"

(17). Such pressures exist, so he seems to suggest, but they do not trouble him too much either.

A clarification

The trend in question is evidently sectarian. However, it is important to note that it is driven neither by religion, nor by any special needs of the population of Jewish patients. Rather, it is nationalist, as the following points indicate, and this makes it particularly disturbing.

First, while the *Halacha* – the Jewish orthodox law and jurisprudence – forbids deceased organ donation, it has no principled objection to living organ donation. Nor does it place any conditions, whether religious, national or other, on such donation. It does not prohibit donation to a Gentile, then. Nor does it prioritise Jewish recipients.

Second, with respect to the disturbing trend in question, the recipients are Jews, but not necessarily orthodox or even religious.

Third, as far as living donations are concerned, the Jewish patients on the waiting list do not form an underprivileged group.

Finally, while the vast majority of donors consists of orthodox Jews, many of them happen to be ultra-nationalist West Bank settlers. The fact that many are “repenters” – people who embraced the religious faith only recently – may partially explain their susceptibility to rabbinical pressures to donate an organ. However, it does not explain their preference for donating an organ to a Jew and only to a Jew. Their nationalism does. This paper focuses on the problem with this particular motivation. Issues pertaining to the donors’ vulnerability and the possibility of undue influence warrant a separate discussion.

What is wrong with conditional-nationalist donation?

The complicity of the Israeli transplant system with this conditional-nationalist trend is undisputedly unethical (masking it behind an ethical cloak makes things even worse). But is it also morally unjustifiable? Moreover, is the trend itself morally unjustifiable?

It is not easy to be sure about the answer. The charity could argue that notwithstanding its silent nationalist ideology, it is not directly exclusionist; thus it should not be perceived as offensive by those whom it does not serve, notably, the Israeli Palestinian population. The charity could even say to this population, "Look, we take care of our people. This is normal. Everybody does it. Why don't you do it too? In fact, we would be more than happy to share our experience with you and help you set up a similar charity for your own people." The charity could also argue that, in fact, it benefits the Palestinians as well. By removing Jewish patients from the waiting list, it effectively shortens it. Regardless of the points made earlier, the donors, the charity and the complicit transplant system could argue that they all save lives, and saving life overrides any objection one may raise.

These arguments may sound convincing. The question is whether they are relevant. I wish to argue in brief that they are not, given the current Israeli political and medical contexts.

Israeli Palestinians, who number more than 1.7 million and constitute about 20% of the total population, are effectively treated and certainly feel that they are treated as second-class citizens. Israel fosters these feelings. For example, it explicitly regards itself as a Jewish state, not a state of and for all its citizens. It discriminates against the Israeli Palestinians in the matters of public funding, social integration, economic status and mobility. It hardly ever allows them to unite with their non-Israeli family, unless they are willing to emigrate. Kibbutzim would not accept Palestinian members. A policy of Jewification of areas densely populated by Palestinian citizens has been followed for decades. Senior politicians and others are calling for the transfer of the Palestinian population or parts of it. Attempts to ostracise Palestinian MPs are also increasing. Even the mere idea of a coalition government with their parties is deemed national betrayal. During the last general elections, the Israeli Prime Minister warned the Jewish voters, "The Arabs are moving in droves to the polling stations." (23) This deeply disturbing bias is all-pervasive. It affects the Israeli healthcare system as well. It has recently been reported that some hospitals separate Jewish and Palestinian women in maternity wards upon the request of

the former (24). Many regard what is currently going on in Israel as some form of apartheid. Recently, the Israeli army's deputy chief of staff suggested a parallel between present-day Israel and the Germany of the 1930s (25). The continuing occupation in the West Bank and the siege on the Gaza Strip, which affect millions of non-Israeli Palestinians, are another matter.

Against this backdrop, a Jewish-sectarian donor-recipient matching programme cannot be perceived as anything but a segregationist, exclusionist enterprise. The Israeli transplant system's pseudo-ethical complicity with the programme thus becomes particularly disturbing. Instead of bringing peoples together, the imperative of the hour, this complicity helps to tear them apart. While saving the lives of the few, it mirrors the murky political stream that threatens the lives of the many. If only for these reasons, it is necessary to bring an end to this complicity.

What is to be done?

In our troubled world, the risk of altruistic individual-to-individual LURD concealing sectarian (and, of course, commercial) donations is likely to rise. Perhaps it may not be avoided completely. However, the international transplant community can reduce it significantly by embracing the default fictitious-but-realistic assumption that something is bound to be wrong with unrelated donations that are directed to recipients identified through the Internet (eg matchingdonors.com), or through third-party organisations (eg *Matnat Chaim*). The system must reject such offers without exception, regardless of how convincing the explicit motives of the donor may sound and irrespective of how close the donor-recipient relationship may seem.

Conclusion

With all respect to patients on waiting lists and their caring doctors, some forms of kidney donation are utterly unacceptable: "donations" from vendors, "donations" from executed prisoners, and also conditional-divisive donations. The Israeli nationalist trend and the complicity of the local and other systems therewith must stop at once. Israel has done a lot in recent years to combat organ trafficking and transplant tourism, phenomena that were once pervasive in the country. It does not need another scandal

to undermine its commendable achievements. Nor does its deeply divided society need it. Nor do Jews worldwide need it. Sectarianism and exclusion have caused them enough suffering.

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The unfair trade: Why organ sale is indefensible

SIBY K GEORGE

Abstract

This paper argues against the proposal of a system of compensated living donation in the global south, especially India, without recourse to essentialist ethics. It relies on the anti-essentialist ethical-ontology of Levinas for the claim that it is the concrete vulnerability of the suffering other, rather than any absolute moral imperative, that makes a market for organs unethical.

Introduction: Situating the question

Organ sale, consensual or not, is prohibited, presuming the absolute inviolability of the embodied person. Criminalisation of the profit motive makes donation to foreigners virtually impossible in India. But Indian law does not criminalise prostitution per se, another type of commercial use of the body. A much abused part of the Indian law is donation with the approval of the authorisation committee to unrelated persons, owing to 'affection' or 'other special reasons'. The black market for organs, however, is active in India - and throughout the Global South - with the increased possibility of living longer, stricter laws against organ sale, and persistent cultural prejudices against living related and cadaveric donation. The exposés of 2016 show that this market has moved from shantytowns, shady clinics, and dubious quacks to elite private hospitals in major metropolises of the country. Around 2,000 Indians sell their kidneys annually, mostly to foreigners, but there were only around 750 legal cadaveric donations in 2015 (0.5 per million population), though showing a steadily rising trend (1). On the other hand, in Iran there is a legal market for organs.

In this context, the question is: why is compensation paid to an organ donor unethical?

My purpose in this paper is to argue against the proposal of a system of compensated living donation in the Global South, especially India, without recourse to essentialist ethics or moral absolutism, according to which an ethical transgression breaks a universal, objective, rationally knowable and natural ethical law. The context of the argument is India and the Global South in general. The term 'culture' is used in the sense that most relevant aspects pertaining to humans are cultivable and transformable rather than natural and unchangeable.

In the first section below, I elaborate on the anti-essentialist ethico-ontological perspective, referring to Levinas, in order to clarify why I reject both the ultra-moralistic anti-commodification and the ultra-triumphalist pro-commodification ethics, which takes transplant for a sort of human right to defy death. In the next section, I argue that a regulated market for organs cannot be unethical in an absolutist-essentialist sense. Rather, it is unethical from the perspective of the vulnerability of victims, especially in contexts where they are coerced to consent to sell their organs out of desperation. I conclude with a brief note on new cultures of dying and living.

Towards an anti-essentialist transplant ethics

Two broad ethical perspectives may be seen in modern western philosophy-essentialism and anti-essentialism. Essentialism, represented in deontological and utilitarian traditions, deduces ethical principles from rationally knowable, necessary, unchangeable metaphysical essences, much like religious ethics before it, based its principles on metaphysical notions such as God and soul. Immanuel Kant's humanity principle - the inviolable dignity of the person - and his notion of the worth of ethical dispositions are drawn from his metaphysics of essential, 'unconditional and incomparable' human nature, which is autonomous, rational and lawgiving. "*Autonomy*," writes Kant, "is therefore the ground of the dignity of human nature and of every

rational nature.” (2: p 85) Further, Kant’s ethics presupposes the three postulates of immortality, freedom and God.

An important strand of philosophy since the late 19th century, seen in the works of figures such as Nietzsche, Heidegger and Wittgenstein, considers the concept of eternal and universal ‘essence,’ hidden from our experiences and language, as a philosophical pretension. Essentialism forces us to forget that what we consider as essential is a historical-cultural construct, contingent upon time and place. Nietzsche writes: “‘Essence,’ the ‘essential nature,’ is something perspective and already presupposes a multiplicity.” (3: p 301) The evolutionary perspective has indeed dealt a death blow to essentialist humanism. Exploring an anti-essentialist stance for bioethics, Stan van Hooft argues that often “the standards of human excellence propounded by essentialist theory are the standards that are native to the propounder of the theory. This is why essentialism is usually oppressive to anyone who is ‘other’ in relation to the essentialist.” (4: p 25)

Essentialist human ontology has become palpably problematic with contemporary technology. The American feminist thinker Donna Haraway argues that traditional binaries such as human-animal, animal-machine, physical-nonphysical have become perceivably untenable with new technology and science. She captures the tangible breach of ontological essentialism in her concept-metaphor of the ‘cyborg,’ which is both organism and machine, real and fictional, as when we implant foreign organs or machines into our bodies, or when we make real imaginative suggestions in science fiction and socio-political discourses. For Haraway, the anti-essentialist ‘cyborg ontology’ can be the basis both of liberation and oppression, but it definitively abandons the idea of a hidden essence behind identity that stokes a fear of transgressing its boundaries. “Liberation rests,” says Haraway, “on the construction of the consciousness... of oppression, and so of possibility.” (5: p 11) If organ transplant was both practically unimaginable and morally abhorrent before, cyborg ontology can explain and defend how new technological and moral-political cultures of liberation from biological and social dominations have legitimately transformed such imagination and ethics.

Taking a broadly anti-essentialist ontological stance, the 20th century French phenomenologist Emmanuel Levinas argues that our actual moral sensibility does not arise from free rational calculation. For example, our unwillingness to get involved in a road accident in fact arises from rational calculation, which restrains our more original moral sensibility. Levinas's ontological explanation for the possibility of ethics hinges on the spontaneous moral response ('responsibility' in his terminology) we feel obliged to have towards the 'face' or the other in her vulnerable exposure - that is, our own embodied-sensual-moral openness to the other - which is enacted through culturally filtered interpretive lenses, when we are faced with a morally needy other human being. Indeed, it is only when we forsake in some measure our own being, essence, freedom and self-interest, and recognise the other person in her otherness, that ethics is possible. Our own sense of self/identity is an outcome of dialogical interaction with the world and others, passively received without our choice and decision, from the earliest moments of our birth. Levinas, therefore, holds that our originary ethical sensibility or responsibility for the other is an aspect of our own subjectivity. "The present is a beginning in my freedom," he contends, "whereas the Good is not presented to freedom; it has chosen me before I have chosen it. No one is good voluntarily." (6: p 11) Of course, we can be either ethical or unethical in the normative sense, accordingly as we respond or not in terms of originary responsibility. Our manifold culturally embedded ethical and legal norms, argues Levinas, are various necessary ways in which we attempt to rationalise and regulate our anarchic responsibility for the other. The latter he calls 'the saying' and the former 'the said'. That is, the original responsibility, which is the ontological communication of goodness, has to be finally expressed in language and culture as science, reason, art, ethics and law. "Responsibility for the others or communication is the adventure that bears all the discourse of science and philosophy." (6: 160) Notice that Levinas does not ontologically explain ethical action in terms of any rational imperative but does so in terms of sensible openness to otherness. Before reason and calculation, morality is an affect. It is not clear in Levinas' writings whether moral sensibility in this sense is an essential human trait. However,

I take it as a concrete and finite possibility of humans as we know them historically.

From the anti-essentialist point of view, the autonomy of the rational agent, which is the foundation for contemporary medical ethics, is a modern cultural-moral ideal rather than an essential human trait. Humans can perhaps never be fully transparent autonomous agents in their concrete situations. The instrument of informed consent, widely used in medical contexts, is a tool deployed for the sake of pragmatic ethical transactions. It is never unambiguously moral. As a matter of fact, in nearly all recent organs trade exposés in India, the medical professionals involved made a legally valid case to their own advantage, relying on the sanctity of consent documents. The cultural process of modernity is still underway in India in a specifically contextual and different manner from the West. Hence, the unqualified reliance on informed consent documentation is that much more suspect in India. It is often an alibi for the medical professional to legally wriggle out of compromising situations rather than the unmistakable guarantor of patient autonomy. In the context of organ transplantation in India, and perhaps everywhere, therefore, a more imaginative, context-specific, and morally sensitive approach towards donors and patients is required on the part of the medical professional.

Anand Gandhi's film *The Ship of Theseus* (2013) powerfully depicts moral ambivalence and different moral responses to organ transplants. In its first frames, we read the classic essentialist problem of the riddle of Theseus's ship: "As the planks of Theseus's ship needed repair, it was replaced part by part, up to a point where not a single part from the original ship remained. Is it, then, still the same ship?" The film skillfully draws our attention to three true-to-life organ transplant episodes, which lead to a reversal of perspective for the subject of transplant. The visually challenged photographer Aaliya finds that a cornea transplant that gives her an overabundance of visual splendor has in fact taken away her photographer's creativity, and she decides to abandon photography. The animal rights activist and monk Maitreya, who refuses liver transplant in the name of his moral ideology and decides instead to die voluntarily, finally opts for a transplant

in his encounter with the terror of death. The successful kidney transplant survivor and carefree stockbroker Navin decides to wage a moral-legal battle against kidney theft and organs trade but is forced into the realisation of the entanglement of the trade in the geopolitical economy of the North-South divide. All three protagonists are united in the final scene of the film in the awareness that they, and a few others like them, are partaking in the life of a speleologist, who had a fatal fall. The instability and essencelessness of identity, and the meaninglessness of essentialist moralism, based on an absolute conception of autonomy, free will and human exceptionality, are the emphases of the film.

The anti-essentialist ethical perspective, I want to argue, disavows both the prudish anti-commodification stance on organ transplant, as well as the triumphalist pro-commodification stance.

As regards the first, I must say that moral cultures do change and contemporary transplant ethics has come a long way. Kant disapproved of organ transplant. "To deprive oneself of an integral part or organ (to maim oneself) - for example, to give away or sell a tooth to be transplanted into another's mouth, or to have oneself castrated in order to get an easier livelihood as a singer, and so forth - are ways of partially murdering oneself." (2: p 547) He disapproved of sexual love except for the purpose of preservation of the species. The nostalgia for permanent modes of being and doing is a powerful myth, rehabilitated by modern philosophy and science, although science itself is witness to foundational shifts in paradigm. Contemporary critical enquiry is in a process of interrogating the residual moral difficulties of modern ethical ideals. The ideal of sacrosanctity of the body, which has crept into modern ethics from traditional morality and has too many skeletons in the cupboard, continues to haunt the views of even perceptive organ trade critics like Nancy Scheper-Hughes, when they uncritically bemoan the death of traditional moralities, as if moral cultures never change (7). The inviolability of the body, enshrined in the ethics of purity and pollution, is often the very reason for violating female bodies and Dalit bodies (8). From a Kantian perspective, scholars sometimes argue that commodification of the body is wrong, despite informed consent.

because they consider “embodiment as a fundamental part of personhood” (9: p 170). Libertarians challenge this, insisting that “one must show why the fact that money is exchanged corrupts the transfer of organs from one person to another” (10: p 141). Indeed, going by the principles of contemporary medical ethics, medical professionals should promote uncoerced organ sale, regulated by informed consent documentation. The self-evident immorality of organ sale flies in the face of Kantian justifications of the voluntary sale of oneself to another in prostitution or pornography (11), in surrogacy, and in the prevalence of the socially condoned practices of voluntary subordination of oneself to another in the exploitative conditions of family, marriage and neoliberal workspaces. In fact, some scholars, after thinking through the Kantian paradigm, have used it to defend sale of organs under ideal conditions (12). Just like sexual morality, which is gradually abandoning a puritanical ethos, medical ethics cannot be blind to the new possibilities offered to the body by modern medicine. From an anti-essentialist perspective of public morality, the conclusion that compensating for organs is absolutely evil is difficult to fathom, if the seller is not harmed by the sale and there are ideal circumstances to give her free consent. Indeed, a desirable culture of easy, unremorseful gifting or even selling of body fluids and body parts, without unreasonable risks and exploitation of the donor/seller, is welcome.

As for the second stance, the modernist belief of death as failure is its basis. A consequence of the denial of death is the technologisation of dying. Another is cryonics (preservation of the body immediately after death at a low temperature in the hope of resuscitating it with advances in medicine), which has already been pursued by a few Americans (13). We haven’t yet ceased to die, though the culture of dying has changed. With advances in modern medicine, and the death scene gradually shifting from home to hospital, and the body being professionally prepared for funeral, our encounter with human mortality and finitude is becoming rather unreal and the longing to live longer insistent. Lewis Thomas, the American philosopher-poet of medicine, argues that Americans “view death as a sort of failure, just as we now look at the process of aging itself as failure” (14: p 3). Pre-modern cultures accentuated the inevitability of dying, tempering

the terror of death with anticipations of immortality. We read in *The Bhagavad Gītā* II:27: "What is born is certain of death/ What is dead is certain of birth./ And so, for what is inevitable/ You must not mourn." The excessively insistent transplant culture, supported by an organ black market, is undergirded by the culture of death as failure. But failure presumes a degree of freedom for the subject. We fail an examination, an interview, an assigned duty, a moral standard. Death was traditionally not a failure because we hadn't been free enough to refuse death. Organs never failed before because we couldn't artificially control their activity; thus there was no organ shortage. They fail today because we are able to replace them when they cease to function. We are now free to refuse death far beyond traditional limits with the aid of medical technologies. Thus, human focus is successfully turned away from other-worldly concerns of tradition to this-worldly lifespan expansion - the new materialistic immortality. But the extreme eagerness to escape death, taking recourse to the new medical technologies, even by plunging another into danger, perhaps signifies the human desire for self-deification. About this condition, Heidegger says the following: "Creation, once the prerogative of the biblical God, has become the mark of human activity, whose creative work becomes in the end business transactions." (15: p 165) The inordinate sacrosanctity of the body, thus, gives way to profane manipulation of bodies to deify finite humans. Scheper-Hughes points out that free market medicine requires "the divisible body and detachable organs as commodities" (16: p 62). In the process, the moral sensibility, arising from human sociality, comes to be compromised. Technologically amplified modern human freedom can take ghostly proportions.

The good we are seeking in organ transplant is humanly desirable freedom from illness, pain and death, as long as possible for finite humans. From an anti-essentialist ethical perspective, this good we are seeking has to steer clear of both prudish anti-commodification moralism and defiant pro-commodification triumphalism. The question of relevance, therefore, is: how far can one push the prolongation of one's life without jeopardising another's good and life itself?

The moral predicament: gifting or selling organs?

The moral predicament concerning transplant ethics stems from the liberal ethico-political ideal of individual autonomy. Libertarian philosophers see the notion of self-ownership as attached to the Kantian principle of treating autonomous individuals as ends in themselves, who cannot be sacrificed for any other end without their consent (17). Why is a person, they ask, forbidden to sell parts of her body to a needy other as the fully autonomous owner of her own body, even as she is encouraged to donate parts of her body under the same assumptions? Autonomy and self-ownership are deeply ingrained assumptions of mainstream contemporary bioethics globally (18). The claim that body parts cannot be sold because the body is fundamental to personhood flies in the face of the claim that they can nevertheless be gifted. The property-based model of autonomous selfhood, on which are based such claims of gifting and selling, is counterintuitive to the way a human becomes a self, an identity.

Against this model, Levinas holds that humans are not discrete, autonomous spirits; their subjectivity is formed in relations with others. Since Heidegger, the self is not to be understood as a thing or property but as 'a way of being.' Hence, ontologically speaking, my responsibility for others comes before my self-ownership and autonomy: "the surplus of my duties over my rights. The forgetting of self moves justice" (6: p 159). The Levinasian ethico-ontological paradigm begins and ends with the other, not the self. Hence, the ideals of individual freedom and rights are justified not because the individual is a discrete, self-owned ego. Rather, it is the responsibility of everyone in society to invest the individual with rights so that she may not be weighed down by the anarchic responsibility that forms her own subjectivity. It is to be remembered that the ideal of autonomy became culturally acceptable in western societies after a hard-fought movement of resistance against the overbearing communal ethos of sacrificing self-interests at the altar of community. Autonomy is not a natural human trait. A culture of freedom is crucial for its cultivation and practice. Levinas insists that a free and equal society of human fulfillment does not entail "a limitation of anarchic responsibility,"

but is conditioned on “the irreducible responsibility of the one for all,” which cannot be “without friendships and faces” (6: p 159).

Kristin Zeiler criticises Levinas’ account of moral experience as an overtly altruistic model for transplant ethics - donation without reciprocation. She, however, recognises that his work can also be understood “as seeking to reach a better understanding of the phenomenology of the experience of feeling the need to come to someone’s aid” (19: p 55). That is, it focuses on the vulnerabilities and concreteness of the asymmetric encounter between giver and receiver. Stephen Frears’s film *Dirty Pretty Things* (2002) depicts the Nigerian immigrant doctor Okwe and Turkish chambermaid Senayas drawn into the murky world of prostitution, drug peddling and illegal organ transplantation in a shady London hotel. Exploitation of vulnerable immigrant bodies for sex and organ harvesting is the main storyline. Calvo and Sanchez observe that the film is a perverse reversal of the emphasis on relation rather than identity/unicity¹ in Levinas’ ethics of hospitable welcome because immigrants fall prey to exchanging their bodies for new passports and new identities (20). Levinas was himself interned at the Nazi concentration camp and does not deny such shocking reversals. The point of his ethical ontology is to explain the possibility of even little acts of kindness that can prevail in situations where each fought for her own bare survival. *Dirty Pretty Things* depicts not only the vulnerability of the immigrant protagonists, but also the moral relation they are able to maintain under threat of police detection and danger to life. Michael Davidson sees in the film the contradiction of dirty/pretty relations between international labour migration, new medical technologies and sexuality. Gross, dirty exploitation, rather than welcoming of the vulnerable other, is a cruel repetition of historical capitalism as depicted in the ‘dirty’ exploitation of vulnerable migrants and the ‘pretty’ side of the happenings — sexual gratification, cheap labour and the ultimate gift of life itself — as they favour the bourgeoisie. “The invisibility of these forces to the consumer of body parts,” writes Davidson, “like Marx’s version of the laborer’s body in the commodity, maintains the surface glamour of touristic London and finesses the illegal traffic in body parts.” (21: p 198)

However, the strong anti-commodification view does not seem to hold water within the anti-essentialist paradigm of Levinas, for whom ethics does not draw from a divine or rational imperative. He is concerned with the nature of ethics after the anti-essentialist recognition of incessant contingency and difference without stable identity - in short, the secular break, Nietzsche's death of God. Moral sensibility gives rise to values, rather than absolute values giving rise to the ethical impulse. Ethics "preserves *difference* in the non-indifference of the Good" (6: p 123). There are manifold ways in which we can be good in a situation. Levinas' goal is to free ethics from enchainment to self-interest. Values and norms express in their difference the ineluctable ambiguity of our originary responsibility for the other. Beyond being, essence and absoluteness, ethical language, enshrined in norms and laws, gives imperfect witness to this responsibility, contingent upon the finite existential imperative of human relations. Ethics is as fluid and indeterminate as a human relationship itself is. Levinas' point is about the culture or cultivation of a sense of responsibility for the other that is self-constitutive. Rather than an obsession with formal absolutes, ethics is attention to human difference.

The logic of global capital, untiringly pursued by most nations, is the resourcification of all beings, as Heidegger laments. For meaningful non-commodified relations and exchanges to freely emerge, the all-encompassing current culture of resourcification and capitalisation of all beings, including embodied persons and their intimate body parts, has to change. Without rethinking neoliberal market relations, singling out the sale of organs as absolutely dehumanising is disingenuous. Assuming this global context, De Castro argues that there could be multiple motivations - ethical, unethical and ambivalent - both to donate as well as to sell organs (22). Critics point out that emotional despair can drive relatives to donate organs just as economic despair can drive nonrelatives to sell them. The system of donation cannot be considered always already fair. Further, donation and trade of organs are both unfair against disadvantaged patients, who are less likely to get a donor (23). Economic and cultural compulsions often coerce financially dependent, uneducated women to be the typical 'altruistic' kidney donor in India for typically men-

receivers (24), which is also the global trend (25). De Castro lists various possible uncompensated and compensated organ giving scenarios, which are not morally transparent. We can multiply such scenarios almost infinitely and our intuitive moral reaction to different scenarios of organ donation and sale vary. From the Levinasian anti-essentialist perspective of the ethics of relation, it is difficult to see what is wrong with compensated donation, provided it does not harm oneself and fosters a vulnerable other. In this paradigm, lawmaking is a response to the moral situation rather than abstract, essentialist, universal, rational discovery of a principle.

Indeed, it might be possible, even from the Kantian perspective of not treating humanity merely as an exchangeable commodity, to imagine an ideal scenario of compensated organ donation in a Rawlsian well-ordered society of the global North. In this vein, Samuel Kerstein argues that we do not consider a well-off person selling an organ under due care to another such person who is unwell, as a case of exploitation, though trading in organs of the poor, even in a legally regulated market, we might consider so. Kerstein shows that the humanity principle is a guide for contextually mediated empirical judgement, not an absolute imperative (12). In other words, if compensated donation is reasonably possible, it is possible in the global north, which today is unfortunately the beneficiary of the black market in organs. A future is perhaps coming when a publicly mediated system of altruism as well as reciprocation (which is but a compensation) will draw the moral boundaries of transplant ethics. At present, however, the traditional romanticisation of unadulterated flesh is powering the popular refusal of both cadaveric and living donation.

Hence, what calls for ethical attention from the anti-essentialist perspective are vulnerabilities of the typically subaltern organ seller/donor in the global organs bazaar, whether black or white. Since not even a partially ideal context for free and fair regulated and compensated donation system is prevalent in the global South today, and since consent in such contexts could often mean tacit succumbing to vulnerabilities, it is morally problematic to

blindly rely on the instrumental feasibility of informed consent documentation to ease legally permissible unrelated donation. At the same time, although the donation system itself is beset with problems and ambiguities, an anti-essentialist (cyborg) perspective cannot be blind to the new medical possibilities available for the body and the legitimate human desire for a longer lifespan. In this context, rather than letting two unjust and legally validated systems of compensated and purely altruistic systems of donation to come into operation, it is reasonable to experiment with and improve the donation system - a somewhat controllable, small-scale system to begin with. The argument is certainly one of choosing the lesser evil in order to honour the legitimate human desire for 'materialistic immortality'. Injustices in the nonmarket system of donation and the black market for organs show that a market system of donation such as the Iranian one can further endanger rather than ameliorate the plight of vulnerable persons. Overcoming organ shortage is not a morally justifiable reason to jeopardise the lives of vulnerable individuals. Compensated donation is morally problematic not because it is an absolute, universal evil but because we are encountering suffering bodies in the global market for organs.

The new anti-essentialist (cyborg) ontology of the body, hidden in the popular notion of body parts as exchangeable socio-cultural resources, which is supporting the new global transplant culture, is manifesting both the possibilities of materialistic immortality as well as new ways of unjustly treating vulnerable others, couched in a discourse of saving lives. While the tenacious refusal of death, the animalistic survival instinct, is understandably human, the right of survival can be truly honored only when Haraway's cyborg imagery of artificial devices replacing human organs with ease becomes feasible for all, assisted by medical technologies and egalitarian politics. Scheper-Hughes observes that a highly visible, media-driven 'surplus empathy' for suffering patients, and the existence of fairly ideal donor care conditions in the global north, give rise to the inaccurate public perception of an invasive surgical procedure as simple and harmless for all. It is unethical to accept organs from vulnerable persons, she argues, because ideal conditions for donating or selling organs do not

exist in their case (16). She sees insinuations of the ancient rite of human sacrifice in the language of exchange, gift and donation (26). Blatant, capitalistic exploitation of vulnerable others is the moral question in the new transplant culture for Scheper-Hughes: "the flow of organs follows the modern routes of capital: from South to North, from Third to First World, from poor to rich, from black and brown to white, and from female to male" (7: p 193). A non-moralistic and anti-essentialist conception of the body can claim moral legitimacy only when it steers clear of exploiting vulnerable bodies.

Surrogacy, prostitution and exploitative employments, though legal, are not morally unproblematic because they too can involve exploitation of vulnerable others, but unlike these, organ sale involves an invasive surgical procedure, leading to permanent removal of an intimate body part, possible health complications, and requirement of elaborate post-surgery care (27). The exploitative conditions persist even in the legal organs market of Iran, where organ-sellers are found to be neglected victims (28). The repeated empirical finding in India is that individuals who sell their kidneys for profit do not actually benefit from the sale in a way that enhances their living conditions. Money received was spent on clearing debts, and average family income came down after the sale, as did average health indicators (29). In *Al Jazeera's* recent episode of the current affairs investigative programme *101 East* on kidney trafficking, the reporter, Steve Chao, focuses on several people in Hokshe Village, known as Nepal's Kidney Valley, where most adults, persuaded by preying organ traffickers and forced by ignorance and poverty, disposed of their organs in Kolkata's transplant clinics (30). "I agreed to give a kidney to the agent," tells a donor. "But I didn't even know what a kidney was." The interviewees are typically men in tears, regretting their moment of error and reporting health complications, inability to work, guilt and stigma, and fear of the organ mafia. Scheper-Hughes clarifies that men who sell their kidneys are frequently labeled weak and disabled, and are rebuffed by fiancées, potential employers and coworkers (16). The well-known Villivakkam episode of the 1990s - India's kidney village - is a classic case of livelihood desperation pushing a tsunami-hit fishing community's women to sell off their

kidneys to pay off debts. A probe in 2007 did not reveal desirable change (31). All recent kidney racket exposés in India continued to validate the morally shocking vulnerabilities of victims. What a Nepalese official told the *Time Magazine* reporter in 2014 appears to be the truth: “I’ve not found a single person who sold their [sic] kidney who is rich.” (32)

Vulnerable victims of organ trafficking in the Global South, however, are preyed on not only by rich westerners. Organ predators are typically rich and privileged citizens. In other words, there could be foreign as well as domestic colonisation or exploitation of vulnerable bodies. The clever hybrid possibilities of cyborg ontology, in this instance, show their ugly side. Lawrence Cohen paints the re-inscriptions of caste coding in transplant culture with reference to the classic 1959 Hindi film *Sujata*, directed by Bimal Roy. In the film, modernity is characterised as nationalistic decoding of caste difference, as a Dalit girl’s rare blood group gives another lease of life to her conservative foster mother and she is romantically engaged with a Brahmin boy. But for Cohen, more than ‘decoding’, modernity is often about a different form of re-inscribing and recoding traditional prejudices. What is eulogised as the disappearance of regressive differences of caste is not a Levinasian welcoming of the face but another form of exploitation, for the sake of materialistic immortality, made possible through transplantation technology. This biopolitics of late capital is the morally worrying factor in the emerging transplant culture (33). Karen De Looze observes that there are powerful Indian mores, which consider gifts as polluting, especially those coming from the lower castes. Payment is considered as negating the gift’s polluting effect, and thereby encouraging organ sale rather than donation. Other culturally coded prohibitory practices for donation that de Looze mentions are the funeral ritual of whole-body cremation and associating the partitioning of body with spirit possession, impurity and unwholesome birth in the next life (34). Family bonds, again, discourage donation by relatives. These social mores and practices, and the existence of a lively black market, make the lower castes further vulnerable in the organs bazaar. Indeed, social and racist prejudices act in various ways to complicate transplant ethics globally. Scheper-Hughes cites kidney tourism to India

from conservative Gulf countries as an example of traditionalists targeting more liberal regions of the world for transplant tourism (7). Clandestine practices of conditional-nationalist living kidney donation are encouraged in Israel (35). Organ donation activists like Sunil Shroff, head of Multi Organ Harvesting Aid Network, Chennai, argue that poor infrastructure and inadequate awareness, rather than culture, are the reasons for India's low donation rates (36). Nevertheless, a 2014 study of 352 relatives of patients, health exhibition attendees, college students and teachers in Delhi quotes lack of awareness, religious beliefs and superstitions, and lack of faith in the Indian health system as reasons for donation hesitance (37). However, cultures are never static. They change with new possibilities, discourses and interventions.

Conclusion: New moral cultures

To sum up, taking an anti-essentialist ethico-ontological perspective, I have argued that both the moralistic anti-commodification stance towards body parts as well as the triumphalist pro-commodification stance are morally problematic. While compensated donation in ideal conditions need not be foreclosed, the present transplant culture of gross exploitation of vulnerable donors does not warrant a system of compensated donation in the Global South. I have, at the same time, maintained throughout the paper that cultures are fluid and do change with new possibilities and appropriate interventions. Ethical public cultures seldom emerge naturally; rather, they call for careful responses to new realities. Hence, I conclude with the suggestion that the emerging new ways of approaching one's own and the other's dying in the global south may be critically reconsidered. As for one's dying, while human desire and medical technology to prolong life - the new materialistic immortality - are morally praiseworthy, the widely prevalent and repugnant transplant culture of affluent persons preying on the body parts of vulnerable individuals in the global south, in the name of free market ethos and their right to refuse death, is morally reprehensible.

Our approach towards the other's dying can be reimagined in terms of our own 'moral immortality' of living in the bodies of others as organ donors, as the speleologist in *The Ship of Theseus*,

which, I think, is the most appropriate way of describing the moral dimension of cyborg ontology, of Levinas' 'other in the same.' In this direction, (i) a counterculture of willing donation may be publicly encouraged among invulnerable citizens under a regulated scheme of necessary medical support and care for donors, (ii) the unrelated donor system may be carefully monitored so that vulnerable citizens are not exploited, (iii) the black market in organs may be eliminated, and (iv) a regulated cadaveric donation system may be set in place to make sure that organs are distributed justly to those in transplant queues, without which public trust in the practice cannot be nurtured. Needless to say, the role of the State, civil society, and institutions of medicine, education, media, and religion, is absolutely central to these countercultures. Because new theologies of cadaveric and living donation can be enormously effective in the context of India, the role of religion in such countercultures cannot be overstated, and fortunately such cultures of change are already on the anvil (38).

Note:

- ¹ 'Unicity', in Calvo and Sanchez, means a coherent identity or oneness

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FMES conducts research and educational programmes as well as advocacy on ethics and human rights in healthcare. Since 2005, it has collaborated with other organisations to organise biennial National Bioethics Conferences, a meeting ground for delegates from India and abroad to report, debate and brainstorm on all kinds of ethical issues in health, healthcare, research and public health.

Indian Journal of Medical Ethics

The *Indian Journal of Medical Ethics* (formerly *Medical Ethics* and then *Issues in Medical Ethics*), founded by FMES, has worked to highlight ethical principles in healthcare and research. It is, till date, the only journal on bioethics and medical ethics published from India. *IJME* has successfully combined the scope and potential of academics, advocacy, knowledge dissemination and public debates. The journal is a peer-reviewed, quarterly journal indexed on MEDLINE, Scopus and The Philosopher's Index.